

CI/CIDSE Conference
on Tuberculosis and HIV
The Challenge of Cure and Care

CONFERENCE REPORT



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TABLE OF CONTENTS

A)	Welcome Addresses	Page: 3
	<ul style="list-style-type: none">• Lord Mayor of the City of Wuerzburg; Jürgen Weber• Executive Director of the Medical Mission Institute; Karl-Heinz Hein-Rothenbücher• Head of International Relations, Caritas Internationalis, Duncan MacLaren• Vice - Chairman of the Executive Committee of the MMI; Klaus Fleischer• Member of the Organising Committee; Klemens Ochel	
B)	Expert Presentations	Page: 9
	<ul style="list-style-type: none">• Tuberculosis and HIV/AIDS: two synergistic epidemics; Peter Godfrey-Faussett• Chemotherapy for Tuberculosis; Jaques H. Grosset• After the health sector reform, whither lung health?; Pierre Chaulet• WHO Research Project of Community contribution to effective Tuberculosis Care in Africa, Dermot Maher• Socio-cultural aspects of chronic infectious diseases: TB, AIDS, leprosy; Corlien M. Varkevisser• Ethical Issues in the treatment of Tuberculosis; Jon Fuller	
C)	Panel Discussion	Page: 37
	<ul style="list-style-type: none">• The Royal Netherlands Tuberculosis Association; Jan Voskens• Information on the German Leprosy Relief Association; Jürgen König	
D)	Presentations by CI/CIDSE - Organisations	Page: 41
	<ul style="list-style-type: none">• Church - specific response to HIV/TB, Mara Rossi• Integration of Tuberculosis into counselling services in Rubaga Hospital, Kampala, Uganda; Oswald Bellinger• Misereor's Approach to Tuberculosis; Ute Küpper	
E)	Lessons Learned	Page: 47
	<ul style="list-style-type: none">• Lessons learnt from the implementation of combined Leprosy / TB Control Programmes; Ari van Wijnen• Quality assurance for microscopy in TB Control Programmes; Gisela Bretzel• Measures to prevent TB transmission in health care facilities; Klemens Ochel• Approaches to address Tuberculosis in prisons of low income countries; Gesine Ruppert-Mann• Brief History of Tuberculosis; National Tuberculosis Centre, USA	
F)	Output of the Conference	Page: 65
	<ul style="list-style-type: none">• Theological reflections in respect to Tuberculosis and HIV/AIDS; Enda McDonagh• Resume of the Conference; Organising Committee - Klemens Ochel• Compilation of the Output of the Conference; Organising Committee• Results of the written evaluations; Gesine Ruppert-Mann• CI/CIDSE Conference on sustainable Health Care, 1995: Compilation of the output of the working groups; Bob Vitillo• List of the Participants	
G)	Figures and Tables	Page: 99

WELCOME FOR THE CI/CIDSE CONFERENCE ON TB AND HIV

Dr. Jürgen Weber,
Lord Mayor of the City of Wuerzburg

*A*t the doorstep of the third millennium we are often talking about the global dimension in the relationship between people, communities and societies. We try to understand what it may mean to live in a global village. These thoughts make us sometimes hesitant. Today's ceremony, however, is a sign of hope and joy because the City of Wuerzburg has the pleasure to welcome delegations from all over the world, from Africa, Asia, the Americas and the wider Europe.

You have come together, to face the challenges of the two most important infections of mankind: TB and HIV/AIDS. It was due to TB that, in Germany, institutions and structures of public health were set up in the last century after the detection in March 1882 of the tubercle bacillus by Robert Koch, the famous researcher.




Today HIV has become a new deadly partner of the so-called "old enemy". In both, industrialised and developing countries, TB re-emerges as a serious problem causing a lot of human suffering. Besides considering the medical facts, we have to realise, that living and social conditions of a growing number of people in our communities deteriorate in a way that the old epidemic shows up increasingly in our cities. Complacency and reluctance to face the challenges are prevailing at all levels. Not only politicians should be concerned but also the medical profession must wake up to its responsibility to develop tools like new drugs and vaccines or efficient programmes. We have to renew efforts to make our communities and decision makers more conscious about the global dimensions of TB and HIV. We have to educate not only our communities but also our health professionals, to recognise the threat and deal with it. Finally, we have to build up global networks and alliances in order to change the environment in which both, TB and HIV, can develop their deadly partnership.

The AIDS Funding Network, AFNG, a group of Caritas and Christian Development

Organisations of Europe and the United States meeting regularly at the CAFOD offices in London, started in 1996 to discuss the need for a better response to TB and HIV. It took three years from the first idea about a conference till today's opening. The relevant needs of the participating organisations had to be assessed and an agreement reached in which setting sharing and exchange with partners from developing and fast developing countries could best take place. I am proud that two development organisations having their seat in Wuerzburg are involved in the facilitation, the German Leprosy and Relief Association and in particular the Medical Mission Institute (MMI). For more than three quarters of this century, the MMI shows, according to its mission of healing and solidarity, that health problems of mankind are global health problems which challenge us to live together in partnership in the global village.

With my best wishes for a successful event, I would like to declare the "CI/CIDSE Conference for TB and HIV – A challenge of Cure and Care opened". Enjoy your stay in Wuerzburg.

Dr. Jürgen Weber
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**Medical Mission Institute**
CI/CIDSE Conference on TB and HIV
9th till 11th March 1999
The Challenge of Cure and Care
 Way to St. Michael,
Main Auditorium 

WELCOME AND PRESENTATION OF THE MEDICAL MISSION INSTITUTE

Karl-Heinz Hein-Rothenbücher
Executive Director of the Medical Mission Institute

*Most Rev. Prälat Heinz,
Honourable Lord Mayor,
Honourable guests from the different countries in the East and South,
Honourable representatives of the Caritas- and CIDSE-network!*

It is a great pleasure for me to most heartily welcome you here in our beautiful old city of Wuerzburg in the heart of Germany. We are happy that you have arrived safely after long travelling and we are trying hard to make you feel comfortable during these conference days at the Medical Mission Institute (MMI).

My special thanks go to the Lord Mayor of Wuerzburg who is hosting us for this welcome celebration in the ancient Wenzel Saal" of the Wuerzburg City Hall. We understand this invitation as another outstanding sign for the fruitful relation and co-operation between our local authorities and the two development organisations having their seat in Wuerzburg and being involved in the facilitation of this International Conference on TB and HIV, the German Leprosy Relief Association and in particular the MMI.

We, the members of the MMI, still feel challenged by the inspiration of our founder, Christoph Becker, a Salvatorian Father, to provide cure and care to the People worldwide according to the healing ministry of the Catholic Church and in imitation of Jesus who devoted himself to the sick to bear witness to the approach of God's kingdom. Since 1922 our Institute has trained and sent more than 400 medical practitioners and nurses to the countries of the South to contribute to the establishing of hospitals and health services. Our founder's inspiration has been reconfirmed and redesigned by the famous preamble of the document "Gaudium et Spes" of the Vaticanum II: "The joy and hope, the

grief and anguish of men of our time, especially of those who are poor and afflicted in any way are the joy and hope, the grief and anguish of the followers of Christ as well." It is the open spirit of this confession that guides us to respond to the new challenges Church-related health services of the countries of the South are facing in this new era of globalisation. In dialogue with the local churches and affiliated organisations we search for ways to improve the health of the poor marginalized populations. In this process, we emphasise the need to adapt measures to local conditions and the importance of sustainability.

Our Mayor asked what it may mean to live in a global village and to solve problems together. I'd like to encourage all the participants of this TB/HIV-Conference to learn and exercise the attitudes of new global neighbours. As we all know from our personal experience, living as neighbours and facing a joint problem is not an easy task. Therefore let's try to listen to each other, to understand the limitations and shortcomings of our neighbours and to define steps for taking common action.

With my best wishes for open discussions, a mutual exchange and a successful conference!

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OPENING REMARKS TO THE HIV-TB CONFERENCE ORGANISED BY CIDSE AND CARITAS INTERNATIONALIS, WUERZBURG

Duncan MacLaren

Head of International Relations, Caritas Internationalis, Vatican City

Member, Caritas Internationalis HIV/AIDS Task Force

Ladies and Gentlemen, Friends

Thank you for the invitation to say a few opening remarks. I do so on behalf of both sponsors of the conference - Caritas Internationalis and CIDSE, International Co-operation for Solidarity and Development - as a present employee of Caritas and as a former Director and Vice-President of CIDSE.

Caritas Internationalis has 154 members throughout the world working in relief, development and social work and CIDSE has a membership of 16 agencies in the more affluent countries of the world funding development projects in countries of the South. What the two networks have in common is that they are both rooted in the Roman Catholic Church, they both have a commitment to the preferential option for the poor and they both have been active in the field of HIV/AIDS since we all became aware of the pandemic many years ago.

Being rooted in the Catholic Church gives us not only our identity but a way of approaching issues such as HIV and TB. The Church's ministry to the sick is obviously as old as the Church itself but the vision that has emerged from the Second Vatican Council is to take the essential tasks rooted in the Gospel - teaching, healing and social service - and to think of them in terms of a Church at the service of society as a whole. Therefore, nothing which touches human life is alien to the Church and its agencies - including illnesses which combine the double taboo of sex and death.

The preferential option for the poor means that, in the words of the Holy Father in *Tertio Millennio Adveniente*, the Jubilee Letter, we must "raise our voices on behalf of all the poor of the world" and particularly the most excluded, those who are at the lines of rupture

in society where few others are, because that is where Christ is and where His Church must be. That is our task as Church agencies - to be present in those places and to be constantly present. Among the most excluded in the world today are still those women, men and children who live with HIV and have to struggle with increasing poverty and scarcer resources.

Taking seriously this option for the poor led Caritas to found a Working Group on HIV/AIDS over 10 years ago and an AIDS Funding Network Group which includes CIDSE agencies to co-ordinate the response of partner agencies in the North to the challenges of AIDS in the South. The Working Group on AIDS has for many years organised seminars to teach frightened priests and sisters, lay people and bishops about AIDS and to encourage them to respond as part of their witness to the Gospel. That has resulted in thousands of examples of practical compassion, pioneering work on theology and AIDS and the signing of a memorandum of understanding with UNAIDS. And this conference.

This conference fits very well into our option for the poorest and our calling to be in those ignored spots of human suffering. In the last edition of *AIDS in the World*, the article on HIV associated TB (TB) states that TB is the most common opportunistic infection among HIV infected patients in developing countries, that TB notification rates generally have risen fourfold in Malawi over the last few years due to the rapid increase in HIV associated TB and that over a quarter of adult deaths in developing countries are because of TB.

But one of the most worrying sentences is: "the association of the two pandemics - HIV and

TB – has occurred in a context of general complacency about TB” followed by: “in the era of AIDS, continued neglect of TB control is unacceptable”. Hopefully, this conference will dispel some of the complacency and ignorance and come up with strategies which can be put into operation by Caritas and CIDSE agencies as we continue to try to serve the poor, the excluded and the sick.

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OPENING OF THE CI/CISE CONFERENCE ON TB AND HIV

Klaus Fleischer, MD

*Head of the Department of Tropical Medicine of the Medical Mission Hospital
Vice-Chairman of the Executive Committee of the Medical Mission Institute*

Ladies and gentlemen,

*Christian professionals, health managers, medical specialists,
Africans, Asians, Americans from South and North,
Europeans, friends, companions.*

Not our individual sentiment for the sick and lost, not our professional responsibility in our catholic, protestant and international agencies alone brought us together to this conference on HIV and TB. It is our mounting anger that the gross imbalance between and within nations deprives an uncountable number of people of the means to care for their individual health and bans them from access to services.

As leading members of the civil society all over the world, the Churches have to make their voices heard with impatience. Crying injustice finds public response only when the Churches themselves accept their responsibility for the wellbeing of people and perform accordingly with all means at their disposal. This needs our professionalism, our acceptance of joint learning and willingness for combined efforts to go beyond boundaries.

The Medical Mission Institute, Wuerzburg, as a professional initiative of Catholic laywomen and -men and all the members of the scientific and organisational committee, especially from Secours Catholique, CAFOD and Caritas Internationalis are happy and proud to facilitate a process of sharing and discussion

about all the qualified experience and knowledge in the South and in the North on TB and HIV. The aim is to strengthen our ability to stand against the tide.

The noted poet, revolutionary playwright and Marxist essayist Berthold Brecht wrote in the thirties an „appeal to a sick communist“ which is equally valid for any person living with HIV and/or suffering from TB around the world today:

APPEAL TO A SICK COMMUNIST

We have heard that you suffer from tuberculosis. We ask from you: don't see in it fate, but an attack by the oppressors who left you barely dressed in damp sheds, hungry.

This is how you were made sick. We command that you take up the fight without delay, the fight against the disease and against the oppression with all possible list, severity and tenacity as part of our fight which has to be fought from weakness, from utter misery, in which everything is permitted which may lead to victory, a victory of the human race over scum. We expect you back on your post, companion, as soon as possible.

Bert Brecht (1898 - 1956) combines in his work, social revolutionary satire and true empathy with the lot of the rightless with radical Marxist agitation.

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CONCEPTUAL FRAMEWORK OF THE CONFERENCE

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Problem Statement

Since the late sixties, concepts of efficient Tuberculosis (TB) control programmes have been outlined. There is no doubt that a number of interventions are known by which TB patients can be cured and the epidemic controlled.

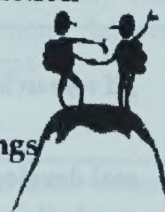
At the end of the second decade of the global spread of HIV, many lessons have been learned also regarding HIV in particular how to assure prevention and care for the infected and affected. Just to mention a few: there is blood safety control, IEC, control of sexual transmitted infections, condoms, treatment of opportunistic infections, voluntary testing and counselling. If the reality shows us that causal factors for TB and HIV are linked, at least partly, must we not bring the 'TB programmers' together with the 'HIV activists', to define common goals and projects, at least for those people who are co-infected? This is what is intended by this conference. The 'activists' can learn the rational of public health, disease control measures and the technicians can learn that there is a difference between disease (biological abnormality), illness (personal perception and living) and sickness (social dimension) and that social, cultural and human dimensions of a health problem may be of even bigger importance than efficient drugs.

Deeper Analysis of Needs

In October 1996, the AIDS Funding Network Group (AFNG) of Caritas Internationalis and Christian Development Organisations (CIDSE) discussed the necessity for appropriate concepts regarding support of projects in relation to TB and HIV. Two observations were general. First of all, TB determined largely the health needs of beneficiaries of projects and secondly, in very many settings the referral of patients with TB to appropriate health service structures posed a huge problem.

**„Action without vision is pointless
vision without qualified action
is fruitless**

**but combined
it could lead to great things**



According to experiences made in several projects, the co-effects of TB and HIV threatened the success of programmes and led to the setting up of parallel structures which competed for scarce resources. In the further discussions it became clear that the support and funding guidelines for programmes with a TB component varied widely among the above mentioned organisations. There was for instance no consensus on criteria for minimal quality assurance of projects. It was decided to study the dimension of the problem and the

constraints mentioned during a 3-day conference. In order to better assess the specific needs of the AFNG member organisations regarding specific topics to be addressed, a study by questionnaire has been carried out during 1997.

Framework of the Conference

Based on these data, the organising committee set up the following provisional conceptual framework. According to the reports, an insufficient quality and inadequate response among CI/CIDSE donors and their partners to TB and HIV became evident. An inadequate understanding and increased competition for scarce resources which caused an inadequate commitment of both CI/CIDSE organisations and their respective partners could be identified as reasons for this unacceptable shortcoming. Furthermore, deficits became clear in relation to inadequate structures of collaboration as well as to poor and inefficient operations.

This conference aims at contributing to a more adequate and improved response in the context of Churches-development aid and the Christian mission of healing. It is expected that through presentations by experts in the field of TB and HIV, sharing of concrete project experience and support policies of donor organisation, CI/CIDSE organisations and their partners will be more committed to TB and HIV work after the conference.

To all the partners involved, it is already evident that growing problems like those of TB and HIV and rising needs of people require new structures of collaboration and co-operation. The conference attempts to lead to more cost-effective operations which are ethically acceptable and conform to scientific evidence. An indicator for reaching this objective will be the formulation of a draft policy and an agenda for action.

After a better understanding of their specific role, Church-organisations have to identify their area of responsibility in regard to norms and standards set up in the context of National Programmes for TB control and care for people living with HIV and AIDS. Therefore, this conference comes at a decisive moment in the work of the AFNG and may open opportunities for streamlined co-operation in the future.

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„If research is the art of the soluble,...

**real development work is
surely the art of the possible
and the sustainable“**



Adapted from
The Art of the Possible

TUBERCULOSIS AND HIV/AIDS: TWO SYNERGISTIC EPIDEMICS

Peter Godfrey-Faussett, MD, MPH
London School of Tropical Medicine and Hygiene,
WHO, UNAIDS consultant

Natural History

Infection with *Mycobacterium Tuberculosis* (TB) occurs commonly in the poorer regions of the world. Annual risks of infection of 1 - 3% per annum lead to 30 - 70% of young adults in such areas carrying the infection. Most of these will not develop disease. Around 10% of those infected will develop active Tuberculosis, of which about one half will be smear positive infectious cases. It follows that each smear positive case needs to infect about 20 contacts to generate one further infectious case, leading to a stable disease incidence. The aim of TB Control Programmes is to reduce the average number of people infected by each smear positive case sufficiently to interrupt transmission.

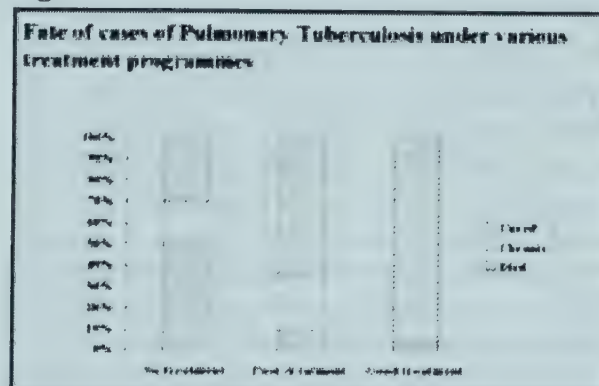
HIV is the single strongest risk factor for progression from latent infection to active disease so that in areas with a high prevalence of HIV infection also, rates of TB are rising. Of the 15.3 million people estimated to be infected with both HIV and *Mycobacterium TB* at the end of 1997, 11.7 million (76%) live in Sub-Saharan Africa. If the same 20 contacts, in the example given above, have a 10% prevalence of HIV infection, 2 will be HIV positive and we can expect 0.8 cases, while the 18 HIV negative contacts would still contribute 1.8 cases of TB. The result is that with no change to the efficiency of the TB control programme, each smear positive case now leads to 2.6 cases, of whom about 1.2 are smear positive. This leads to an epidemic. TB control programmes therefore have to not only cope with the additional cases of HIV-related TB, but they have to do so more efficiently if they are to interrupt transmission.

In Zambia, from 1974 to the early 1980's the incidence of TB was almost constant at around 100/100,000 population/year. Following the arrival of the HIV epidemic, rates have risen fourfold to more than 400/100,000/year.

Similar rises have been reported from several other countries badly affected by HIV.

The historical development of the HIV epidemic has been well documented and UNAIDS issues regular updates of their best estimates of seroprevalence for each country and for various population groups. Latin America saw early cases and rates have risen gradually since. Africa has rapidly become the continent with the highest prevalences and the peak of the epidemic has drifted southwards over time. Asia remains the most frightening prospect for the future; the epidemic arrived a little later but has risen in a few countries and the population is so large that small percentage increases mean huge numbers of people affected. While two thirds of the thirty-something million people living with HIV live in sub-Saharan Africa, the epidemiology of HIV is characterised by its focal nature. Thus, within the sub-Saharan region there is more than a 10 fold difference between countries and within countries there is often considerable variation between provinces or between rural and urban areas. Even within one city there may be considerable variation between apparently similar residential areas.

Figure 1:

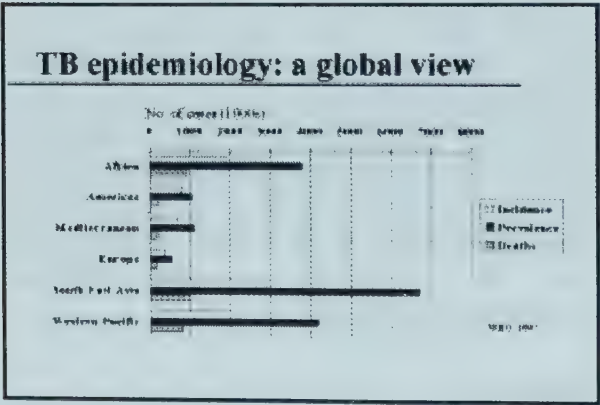


When the UNAIDS' estimates of adult HIV seroprevalence are plotted against the Global TB Programme's estimated TB incidence for

African countries, we see a striking relationship. None of the countries severely affected by HIV have been successful in keeping TB rates down. In these countries 60-70% of TB cases are also infected with HIV. In countries with severe HIV epidemics, it is not possible to control TB without controlling HIV.

While the epidemiology of HIV is focal in nature, TB is much more evenly distributed across the poorer countries of the world. More than half the global burden of TB occurs in four highly populous countries: India, China, Indonesia and Bangladesh. When the same estimates of HIV and TB are plotted for countries in Asia and the Pacific regions, there is much less impact. Thus countries with moderate HIV epidemics may still avert the huge increases in TB if they are able to contain HIV and there is still an opportunity to improve TB control before the flood arrives. The outcome of HIV prevention efforts in these countries will have huge consequences for the subsequent burden of TB.

Figure 2:



The Interaction between HIV and TB

The biological interactions between HIV and Mycobacterium TB are increasingly well understood. HIV is the strongest risk factor yet identified for progression from latent infection with Mycobacterium TB to active disease. People living with HIV infection (PLWH) are also more susceptible to rapid progression of primary infection. Recurrence rates are higher, and may occur through relapse or through reinfection. Most patients with HIV related TB have typical clinical patterns. However, they are more likely than those without HIV infection, to have less typical manifestations, with fewer bacilli in the sputum, less cavitation

and more infiltration in middle and lower zones on chest radiographs, more disseminated disease and more features of primary TB. Drug reactions, particularly skin eruptions are more common in PLWHs, notably to thiacetazone, which may lead to life threatening reactions. The advent of highly active anti-retroviral therapy (HAART) may also lead to serious problems in the few who are able to afford it, since the protease inhibitors are contra-indicated while taking rifampicin. Drug resistant TB has been associated with HIV, particularly in the USA, where HIV related TB may also be associated with other factors that decrease access to health facilities such as intravenous drug use and migrancy.

Mycobacterium TB also enhances the replication of HIV, leading to higher viral levels and to more rapid progression of HIV disease and shorter survival in PLWH who develop TB compared to those who do not.

The Impact of HIV on TB control

In countries with severe HIV epidemics (say > 5% adults infected), the impact of HIV on TB control can be broadly divided into:

- increased burden
- more difficult diagnosis
- treatment issues
- increased mortality and morbidity
- sociological responses to stigma
- institutional transmission
- possible increase in drug resistance

Increased Burden

In the developing world, more than 50% of young adults are infected with Mycobacterium TB, when these people become infected with HIV they are likely to develop active TB. Careful cohort studies in different countries suggest that 5-10% of dually infected adults will develop TB each year. If the HIV seroprevalence rises as high as 10% of the adult population, 100-200 new cases of HIV-related TB can be expected per 100,000 total population. In most countries, this will represent at least a twofold increase in numbers of cases.

The increase in burden of disease is particularly severe in the urban areas, which have traditionally had high incidence rates of

TB and have now also got the highest HIV seroprevalence rates. At the level of the health centre, particularly in urban settings, the increased burden affects every aspect of the DOTS TB control strategy, leading to a downward spiral of TB control:

1. Human and laboratory resources that were barely adequate before the HIV epidemic are no longer able to cope.
2. The rapid throughput of patients with respiratory symptoms, makes it difficult to diagnose cases accurately so that both over- and under-diagnosis occur.
3. Other HIV related morbidity stretches health services still further.
4. Over-stretched resources make adequate follow up, including tracing of defaulters and sputum examinations at 2, 5 and 8 months more difficult to accomplish.
5. The increased burden leads to increasing dissatisfaction with working conditions. The poor morale of staff leads to deterioration in the interaction between patient and clinician and combined with long waiting times this results in patients choosing to seek alternative care to the government health services. In some countries utilisation has fallen significantly, despite evidently of high levels of HIV related morbidity in the community.
6. Accuracy and completeness in recording of attendance and sputum results fall.
7. Logistics for drugs, stationery, sputum pots, laboratory reagents etc. are stretched beyond capacity

Diagnosis and Treatment

In addition to the effect that the increased burden has on diagnosis, it is also more difficult to diagnose individual cases, as mentioned above.

Thiacetazone is gradually being used less and less. Nonetheless, 90% of those living with HIV do not know their status and TB can occur at early stages of HIV infection before advanced immunosuppression leads to other hallmarks that make a clinical diagnosis of HIV probable. It will therefore not be possible to prevent some serious adverse reactions occurring. This leads to patients choosing not to take their treatment and to clinicians finding "excuses" to use short course regimens or

ethambutol continuation phases, which may lead to logistic difficulties in predicting how many drugs to order.

Mortality and Morbidity

Even in programmes that are using an efficient DOTS strategy, mortality in HIV positive patients remains high. Most of this mortality is due to non-tuberculous pathology. This leads both to loss of the community's confidence that the TB programme is really able to cure TB and also to deterioration in staff morale as they lose their power to treat patients effectively.

Patients with TB and HIV are also often incapacitated by other HIV-related pathology making it more difficult for them to visit health centres or dispensaries for follow up visits. Patients with multiple social and medical problems may not consider their TB treatment the most urgent priority.

Stigma

The association of TB with HIV is widely recognised in communities bearing the brunt of the dual epidemic. HIV remains a highly stigmatising infection. UNAIDS estimates that 90% of people living with HIV are not aware of their status. TB already carries its own stigma but the association with HIV is becoming widely recognised so that some patients may choose not to attend health facilities through fear of being diagnosed with TB and by association with HIV.

Misconceptions about TB and HIV also lead to some health care workers worrying about the risk of catching HIV from their patients. Other staff may discriminate against TB patients, perceiving them to be less deserving of care through association with HIV infection.

Nosocomial and Institutional Transmission

Patients with cough, who may have undiagnosed TB, and patients with other symptoms are bound to mix in the wards and waiting areas of hospitals and clinics. The high HIV seroprevalence among hospital inpatients and those attending clinics, facilitates spread of TB. As the HIV prevalence rises in the general population, institutional transmission also

becomes a serious concern for those working in health care facilities or living in crowded surroundings in other institutions such as prisons, mines or barracks.

Drug Resistance

Several outbreaks of drug resistant TB have occurred in HIV positive patients in the US. However, HIV infection in the US congregates with a variety of behavioural patterns that may confound the association. In Africa, where HIV-related TB is more widely distributed in the general population, the limited data shows little, if any, additional risk of drug resistance in HIV positive compared to negative patients.

In summary, HIV has adversely affected TB control programmes both directly through increases in caseloads and more difficult diagnosis but also indirectly through its effect on health seeking behaviour and the interaction between patient and provider at the health services. The control of TB in areas with a high prevalence of HIV infection is therefore, to a considerable degree, dependant on the success of the HIV control programme.

Impact of TB on HIV Control Programmes

Although active TB increases viral replication in individual patients, leading to more rapid progression of their HIV disease and decreased survival, there is no evidence that TB leads to enhanced transmission of HIV. TB therefore has little direct effect on HIV prevention. However, TB is one of the commonest complications of HIV infection and so accurate diagnosis and effective treatment of TB become two of the most important components of any HIV care programme.

It is also possible to prevent some cases of TB in PLWH who have not yet developed active TB. The risk of a woman living with HIV developing TB is about a third, similar to the risk of passing her infection to her unborn child. However, there are considerable operational challenges to ensure that patients with active TB are not given preventive therapy when they need full treatment. Failure to exclude active disease adequately will lead to the development of drug resistance which will be much more difficult and expensive to cure.

TB patients are also an easily identified group who have a higher prevalence of HIV infection than the general population. They are therefore a suitable target for interventions to reduce further transmission of HIV. Surveillance of HIV seroprevalence in TB patients can also provide additional data on trends in the HIV epidemic and in particular allows comparison between males and females, which is not possible for many other groups used in surveillance. In summary, TB diagnosis and treatment should be vital components of the HIV care programme.

"In areas with severe HIV epidemics, the control of TB is, to a considerable degree, dependant on the success of the HIV control programme." – Peter Godfrey - Fausset

Traditional TB control programmes have focussed on the district hospital for diagnosis and case management. Increasingly, however, the heavy burden has led to decentralisation of case-holding and to a lesser extent of diagnosis. An example would be the "Community Contribution to TB Care" project that is assessing the feasibility and cost-effectiveness of eight community-based TB case-holding initiatives in six African countries.

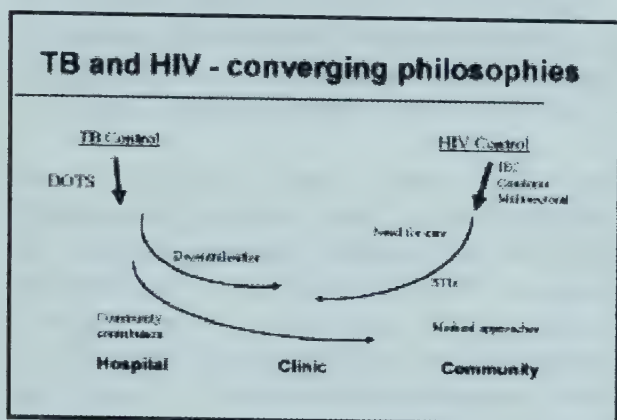
HIV programmes, on the other hand, have traditionally focussed on a multi-sectoral and community based approach for public education, distribution of condoms and home-based care. More recently, the focus on sexually transmitted infections, the need for appropriate clinical care, prevention of mother to child transmission and access to anti-retroviral therapy have led to more involvement of secondary and tertiary health care services. Despite these converging needs, examples of effective collaboration between TB and HIV programmes are rare.

Approaches for a more Intensive Concerted Management

90% of people living with HIV are not aware that they are infected. (The segments of the circles in the figure represent those who know their HIV sero-status) Many have in the past chosen not to be tested, often citing the lack of

any treatment as the reason. The proportion of people who choose to be tested is smallest among those who have no symptoms and who make up the majority of people infected with HIV. As symptoms develop, a few people choose to find out whether HIV is likely to be the cause. Those with more advanced HIV-related disease are more likely to be tested by the clinician as part of their clinical management. Those who discover that they are not infected with HIV (the top circle in the figure) have a strong motive to ensure that they remain so, which can be translated into behavioural change by appropriate counselling.

Figure 3:



In those who have no symptoms but are HIV seropositive (the second circle), counselling aims to prevent ongoing transmission of infection as well as to offer psychosocial support to the individual. As many as 50% of these people will subsequently develop active TB. Counsellors therefore need additional training to include appropriate advice to ensure that their clients are diagnosed promptly. TB preventive therapy is also most feasible in this group, since exclusion of active TB is less difficult.

In those who already have symptoms of early HIV disease (the third circle), the challenge is to detect active cases of TB early and to treat them effectively. Not only will early case detection prevent ongoing transmission of TB, it will also slow the progression of the HIV infection.

Finally, those with advanced HIV disease (the bottom circle), many of whom are housebound and looked after by home based care teams from churches or community organisations, may be unable to visit their local clinic for

supervision of TB treatment and so may default and develop chronic or drug-resistant disease.

There are therefore considerable opportunities for synergy between TB and HIV programmes. The decentralisation and increasing autonomy for districts that health sector reform is bringing to many countries should be used as an opportunity to enhance the concerted management of the dual epidemics.

Possible examples include:

- **Training**
Staff providing TB diagnosis and treatment services need training from HIV programme staff on supportive counselling and clinical care for HIV-related problems. They will also need further training to maintain high diagnostic standards as HIV related lung disease increases. HIV programme staff and those involved with caring for PLWHs need training from TB programme staff to ensure that patients who develop symptoms of TB are assessed promptly and referred for sputum examinations and treatment when necessary. Staff working in hospitals and also those in other institutions with a higher than average prevalence of HIV need joint training from both programmes to establish suitable procedures to minimise the chances of institutional spread of either infection and to detect active cases early.
- **Community care**
As HIV programmes develop home based care schemes, so TB programmes consider community based observation of treatment. Some of those being visited by the home based care team will need observation of treatment, others will need referral for sputum examination. Some of those having their treatment observed will need additional care and support at home, others will require counselling as anxieties about HIV become apparent.
- **IEC, manuals and guidelines**
- **Advocacy**
- **Surveillance**
TB patients may be a useful sentinel group in HIV surveillance activities, particularly in countries where the epidemic is still

early. However, in some settings there are marked gender differences in TB notification rates, making interpretation of differences in HIV seroprevalence difficult. In countries with advanced HIV epidemics, the majority of TB patients may be HIV-seropositive and offer the opportunity for targeted HIV related interventions.

- **Collaboration with NGOs**

While NGOs and community based organisations have been at the core of the response to the HIV epidemic, TB control has tended to be centred on district health services. Greater collaboration with communities would help to spread the weight of the burden of the two diseases.

The vision of NGOs must be long enough to establish long-term solutions to the difficulties facing patients and their communities. Often this will mean working with government health services towards effective care and prevention of both diseases and cure of TB and STDs. Short-term goals may actually reduce the chances of building appropriate systems for the future.

- **Social mobilisation**

Both HIV and TB affect those who are often least able to push for adequate care and support. Social mobilisation and organisation might enhance the pressure that needs to be applied to decision-makers to raise their awareness of the issues.

Dangers of Increased Collaboration between Programmes

Both TB and HIV programmes in developing countries have limited human and material capacity. There is therefore a very real danger that any additional activities may lead to a deterioration in the services currently being provided. The primary goal for TB control activities must remain the diagnosis and cure of infectious cases in order to reduce the burden of infection with *Mycobacterium TB* on the next generation.

The principles of TB control have been established over several decades. Before the development of TB chemotherapy, around 50% of TB patients died, 30% self-cured and 20% remained as chronic and infectious cases.

With the application of an efficient TB programme more than 96% were cured. However, review of poorly functioning programmes showed that while the mortality was rapidly reduced to around 10%, the cure rates were not high enough and the result is an increase in chronic cases (around 25% in the studies reviewed by Grzybowski in 1976) compared to no treatment at all. From an individual or a clinician's point of view, it is better to have some TB treatment than none but from the public health viewpoint no treatment is better than some. The point is brought home still more forcefully when one considers the risk of drug resistance among the chronic cases. If collaboration leads to TB programmes providing less good care or to community-based HIV organisations providing sub-optimal care for TB, well-intentioned efforts may lead to worse scenarios.

On the other hand, without better collaboration, it will become increasingly difficult to provide existing services, as outlined above. Furthermore, the ongoing reforms of the health sector in most countries will lead to increasing integration at the district level. The challenge therefore is to harness the capacity of both programmes and their partners, the communities they serve and the NGOs involved, in order to minimise the impact of the dual epidemics.

Role and Responsibilities for Church Institutions

What should be the responsibilities and expectations of church organisations?

- **Social mobilisation**

The Church's long engagement with communities and their concerns puts her in a strong position to mobilise support.

- **Political engagement**

The rising burden of both HIV and TB needs far greater political commitment than has been witnessed in most settings. Resource allocation, open discussion and non-discriminatory policies have been part of the recipe for the successes witnessed in some of the few countries that have encouraged the inclusion of HIV on the political agenda, such as Thailand and Uganda. Church organisations are usually well-respected and stable platforms from which to encourage the political debate.

- Long-term vision
The need for a long-term vision has already been highlighted
- Complement or strengthen government structures as has the need to work with government structures.
- Share community based lessons
Community and church based organisations have been quick to establish care for the needy and terminally sick with HIV infection. As the burden of TB cases overwhelms the available government health services, more and more people will require care in the community and the lessons learnt already must be shared.
- Promote technical principles
On the other hand, as outlined above, well-intentioned charitable efforts need to be guided by the difficult public health realities of TB control.

Conclusions

In closing, let me summarise a few simple truths:

1. As HIV rises, TB control fails
2. Community capacity is there to be harnessed
3. Technical principles of TB control must not be lost
4. Additional targeted TB control efforts are needed
5. HIV prevention strategies need implementing
6. HIV care strategies must include diagnosis, treatment and prevention of TB
7. Church organisations must complement and strengthen government efforts.

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CHEMOTHERAPY FOR TUBERCULOSIS

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The Birth of Standard Chemotherapy for Tuberculosis

In the famous paper dated March 24, 1882, after having described the series of experiments that led to the discovery of the organism responsible for Tuberculosis (TB), Robert Koch concluded that, for the control of TB, *"First of all, the sources from which the infectious material flows must be closed as far as is humanly possible. One of these sources, and certainly the most essential one, is the sputum of consumptives..."*. Though visionary, the conclusion of Robert Koch took 61 years before being turned into reality by the discovery of streptomycin in the fall of the year 1943 by Albert Schatz, Betty Bugie and Selman Waksman at Rutgers Agricultural College, New Jersey, USA. Unfortunately, the use of streptomycin alone in patients with

cavitary pulmonary tuberculosis (those that we would call now the smear-positive patients) has had an unpredicted consequence: in 3 months' time, 80% of patients were harbouring streptomycin-resistant bacilli in their sputum and failed to be cured.

The explanation of such a sad observation is simple: before treatment, the pulmonary cavity contained a large bacillary population of about 10^8 (100 million) bacilli and among them some, 10 to 100, spontaneously occurring streptomycin-resistant mutants. The treatment with streptomycin killed the great majority of bacilli that were normally susceptible to streptomycin but remained inactive against resistant mutants that continued to multiply and took progressively the place of the susceptible ones, in other words were selected.

Two factors played a decisive role in the selection of streptomycin resistant mutants, the size of the bacillary population, i. e. the number of bacilli in the lesions and the high antimicrobial activity of streptomycin. If the size of the microbial population had been limited, as is the case in TB meningitis or in miliary TB, then the microbial population would have contained no resistant mutant and the treatment with streptomycin alone would have cured the patient. Actually, that is exactly what occurred when patients with TB meningitis or miliary were treated with streptomycin. These always fatal forms of TB were cured by the miracle drug streptomycin. If streptomycin had not been as potent against the tubercle bacilli as it was, like some of the drugs which were discovered later, the response to treatment would have been inferior and the selection of drug-resistant mutants would have occurred later. To make a long story short, the more potent a drug, the more prone the drug to induce resistance in case of monotherapy.

In the late 40s, it was clearly understood that there was no hope to cure patients with cavitary pulmonary TB with any single drug because it was impossible to prevent the selection of resistant mutants to that drug. The prevention of streptomycin-resistance became possible when, in 1946, Conteben (Thiacetazone or Tb1) was discovered by Domagk and para-amino-salicylic acid (PAS) by Lehmann, and, in 1951, isoniazid (INH), first synthesised in 1912, was recognised as a very potent drug against the tubercle bacillus. Used in three-drug combination, usually streptomycin, isoniazid and PAS, each drug was active against the mutants resistant to the other drugs and prevented their selection with the result that the sterilisation of the lesions progressively took place and the patient was finally cured.

The main question that was raised as soon as the problem of the prevention of drug resistance was solved was the total duration of drug administration needed for killing all or almost all of the drug-susceptible bacilli present in the lesions to prevent their subsequent multiplication and resultant relapse after cessation of treatment. Because a small number of drug-susceptible organisms, called

persisters, survived deep in the lesions for a long period of time after the sputum became smear- and even culture-negative, the treatment with the three-drug combination, streptomycin, isoniazid and PAS had to be of long duration to reduce to an acceptable level the proportion of relapses after discontinuation of treatment. In practice, the ideal or maximal length of time was 18-24 months and the minimal 12 months to reduce the percentage of relapse to 10%.

The Field Implementation of Standard Chemotherapy

In industrialised countries, the success of free-of-charge, well organised standard three-drug therapy was tremendous. For instance, the average TB death rate in the USA that was about 40 per 100,000 in 1945 fell to 4.4 per 100,000 in 1960. The progress towards the control of TB was so evident that, in 1960, it was hoped that *"TB can be extinguished as a public health problem"* (Approach to zero for TB. Public Health Reports 1960; 75:103-106).

In spite of its optimism, we know now that such a hope was far from realistic. In the developing countries, unfortunately, the clinical effectiveness of chemotherapy was hampered by many operational factors. Historically, the first was the need of hospitalisation for the delivery of treatment. A remarkable study conducted by the Madras TB Chemotherapy Centre in the late 50s demonstrated that ambulatory treatment was as active as hospital treatment, provided that the regular intake of all antiTB drugs by the patients be well organised, i.e. in one way or another be supervised by the health staff.

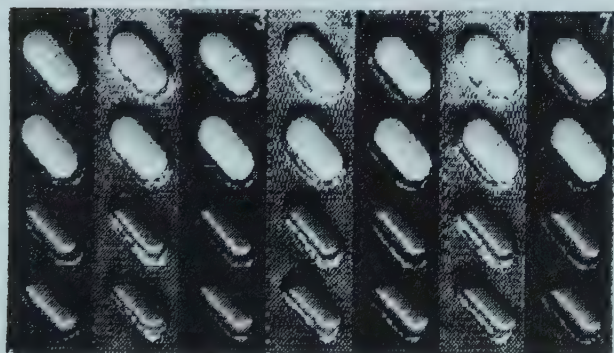
As supervised daily intake of drugs was difficult to organise, fully supervised intermittent administration of drugs was tried as early as in the beginning of the 60s, again in the Madras TB Chemotherapy Centre. After an initial intensive phase of daily treatment, aiming to reduce as much as possible the bacillary content of the lesions, the patients were given twice-weekly streptomycin plus isoniazid, the latter drug being given not at the daily dose of 5 mg/kg but at a dose of 15 mg/kg to compensate for the intermittent administration.

Used in that context, the intermittent treatment was as effective as the daily treatment and therefore permitted the fully supervised administration of drugs to the patients, especially in urban settings. Despite universal awareness that the regular intake of drugs by patients was crucial for success of treatment and the possibility of full supervision was offered by intermittent administration of drugs, only the information that ambulatory treatment was as effective as hospital treatment was remembered by the people in charge of health without duly consideration given to the compliance of health staff with regulations governing successful treatment and the compliance of patients with taking their medications regularly. Added to the lack of adequate drug supply and diagnostic facilities, the absence of a National TB Programme resulted in a failure of TB control in a majority of countries.

The Short-Course Chemotherapy for TB

A radical change could have happened when rifampicin became available in 1967 and was demonstrated to be effective not only against actively multiplying tubercle bacilli but also against the persisters that were responsible for relapses after treatment completion. In combination with streptomycin and isoniazid, rifampicin effected the cure of patients in a treatment period of 9 months, i.e., half the average time required with the three-drug combination streptomycin, isoniazid and PAS! The addition of pyrazinamide, a very potent drug against organisms located in an acid environment, to the streptomycin, isoniazid and rifampicin combination further increased to almost 100% the effectiveness of chemotherapy and resulted in the 6-month short-course chemotherapy for TB.

Figure 4: Blister Pack for TB Treatment



Streptomycin, that was initially included in the 4-drug combination, was progressively replaced by ethambutol, a drug less potent than streptomycin but orally administrable and therefore operationally more convenient, especially in the HIV infection context. The daily 6-month standard short-course chemotherapy that became routine practice in industrialised countries consists in an initial intensive phase of 2-month duration with the four drugs, rifampicin, isoniazid, pyrazinamide and ethambutol followed with a continuation phase of 4-month duration with only rifampicin and isoniazid.

In order to facilitate the full supervision of treatment, it is possible to replace the daily drug administration by a three times weekly administration, on the condition that the doses of isoniazid, pyrazinamide and ethambutol be increased in consequence. Rifampicin should always be given at a dose of 10mg/kg daily or intermittently because increasing the dose might result in serious side effects if the drug is not given daily. Finally, in countries where it is difficult for various reasons to give rifampicin during the whole course of treatment, the continuation phase may consist of daily isoniazid plus ethambutol (or thiacetazone if the toxicity of that drug is acceptable) for 6 months. In that case the total duration of treatment is 8 months and no more 6 months when rifampicin is given throughout the treatment.

The drug regimens are the same for all forms of TB, for all patients whatever their age or the presence or not of a HIV coinfection. Despite the increase activity and shorter duration of anti-TB treatment, the average TB fatality rate remained well over 25 % in developing countries. In addition, resistance to both rifampicin and isoniazid, known as multi-drug resistance or MDR, became common for large numbers of patients in many developing countries and for patients in developed countries who live in socio-economic conditions close to those prevailing in the developing world. In other words, the development of an effective treatment of TB is a real triumph of the medical science but its successful implementation to all patients in need, a complete failure. Even worse, the

misuse of antiTB drugs is creating drug resistance without curing the patient but jeopardising future generations of patients.

"The development of an effective treatment of tuberculosis is a real triumph of the medical science but its successful implementation to all patients in need a complete failure." – Prof. Jacques Grosset

What should be done for an Effective Control of TB?

The solutions to existing difficulties lie mainly in a mobilisation of manpower and resources both in industrialised and developing countries to implement the Directly Observed Therapy strategy (DOTs) recommended by the World Health Organisation. In industrialised countries, political commitment to assure effective treatment to all who need it, should be renewed, some specialised clinics should be maintained where they are needed for the implementation of DOTs, the search for new drugs should be actively supported and adequate measures should be taken to limit the diffusion of MDR tubercle bacilli.

In developing countries, all influential personalities including public health managers and politicians should understand that successful completion of therapy, in other words the cure of patients, is the responsibility of the provider who undertakes to treat TB patients, and that chemotherapy can be successful only within the framework of the overall clinical and social management of patients and their contacts.

The DOTs strategy recommended by WHO and all experts in the world should be applied because its five components are the minimal prerequisites for a successful intervention against TB. These five components are the following:

- government commitment
- case detection by microscopy
- short-course chemotherapy administered free of charge, under close control (of course, the way to organise the control depends upon the local facilities and may involve different partners)
- regular drug supply
- establishment and maintenance of monitoring mechanisms of case detection and treatment outcomes.

The absolute need for a regular supply of drugs and for the patients to really swallow all prescribed drugs at an adequate dosage should be re-emphasised in all settings. The use of combined drug formulations is strongly recommended as well as the use of drugs included in blister packs. All those involved in the care of TB patients should realise that care enough is not sufficient. Their objective should not be to treat patients but to cure them. If not they might do more harm than good.

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AFTER HEALTH SECTOR REFORM, WHITHER LUNG HEALTH?

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Introduction

Health sector reform has been on the agenda for a number of years, particularly in developing countries where there is a political

need for reform even before the conditions or the content have been defined. This is why a critical analysis of the future of respiratory health in the context of health sector reform is

crucial. This analysis will follow three main themes:

- Firstly, what is health sector reform?
- Secondly, an analysis of its partial impact on tuberculosis control and the management of respiratory disease in developing countries, and
- Finally, beyond reform, the promotion of the concept of 'lung health', the real challenge of the future.

What is Health Sector Reform?

At the Alma Ata Conference in 1978, the strategy of 'Health for all by the year 2000' was adopted. Its basic principles were: the development of the peripheral health services, an intersectorial approach, and community involvement in support of the health policies. During the period 1978 - 1987, several obstacles came to light, adding to the usual weighty resistance to change:

- the so-called world-wide economic crisis and the neoliberal responses from high income countries;
- the increasing debt servicing in the developing world;
- the creation of 'structural adjustment programmes', under the aegis of international financial organisations, which has led to the progressive disengagement of the state from social budgets (particularly health budgets) in developing countries.

In 1987, a first statement from the World Bank enumerated four measures which were to be used as the foundation of health sector reform: 1) introducing user fees in public health services; 2) developing health insurance systems; 3) fostering the development of the private sector; 4) decentralising the management of public health services.

Why and how did poor countries find themselves so literally swept away by the health sector reform? There are several reasons why these decisions were taken. The profound, real reasons are the cuts in financial resources allocated to public health budgets, and outside conditions imposed on poor countries in order to allow them to obtain bank loans and donor support. Other reasons, which were not less real, but which served as a pretext or basis for

new decisions, were the need, felt by both the population and the health workers of the country, to make changes in a health system that was ineffective and old-fashioned, because available resources were being used inefficiently, because people did not have access to the health services they needed (due to changes in the demographic structure of the population, and rapid and often uncontrolled urbanisation), and finally, because the health services did not provide what people wanted - in the public sector they faced unmotivated health personnel, overlong waiting lists and drug shortages, while in the private sector there was the risk of financial exploitation, and no guarantees against bad medical practice.

'Investing in Health' - Strategy

All of these reasons, implicit or explicit, were smoothly delivered in an apparently consensual discourse: health sector reform was intended to 'improve the equity, quality and efficiency of the health services.' It was not until 6 years later, in 1993, that the World Bank, in its annual report 'Investing in Health', provided a more structured response on the content of the reforms required, even though a number of the measures recommended by its experts contradicted their declared objectives:

- to foster an enabling environment for households to improve health:
 - pursue economic growth policies that benefit the poor;
 - expand investment in education, particularly for females;
 - promote the rights and status of women (...).
- to improve government investments in health:
 - reduce government expenditures for tertiary care facilities, specialist training and discretionary services;
 - finance and ensure delivery of a public health package;
 - finance and ensure delivery of essential clinical services at least to the poor;
 - improve the management of public health services.

- to facilitate involvement by the private sector:
 - encourage private finance and provision of insurance (with incentives to contain costs) for all discretionary clinical services;
 - encourage private sector delivery of clinical services, including those that are publicly financed;
 - provide information on performance and cost.'

In the way it was conceived, health sector reform is the product of a monetarist vision, based on blind confidence in the 'market' and 'free trade' in order to ensure the socio-economic development of the poorest countries. It is therefore basically a reform of the financing of the health sector, where the users of the services are seen only as consumers, or payers (directly or indirectly).

To aid 'developing' countries to reorient their expenditure so as to reinforce the resources allocated to primary health care, by applying a 'minimum package of health activities' (MPA), the 1993 World Bank Report proposed that governments apportion the following sums in their public health budget:

- 12 dollars per capita per year (on average) in low income countries (in 1990, they had an income level of on average \$350 dollars per capita);
- 22 dollars per capita per year (on average) in middle income countries (in 1990, they had an income level of on average \$2500 per capita).

The reality of applied measures of reform

What measures have actually been applied in the name of 'health sector reform' in many low income countries, particularly in Africa? The most frequent, and the most constant, are the following. Cuts in public health expenditure have been obtained firstly by reducing, and then cancelling, equipment; then by cutting the 'drugs' budget (most often due to frequent and increasing shortages); and finally, by cutting staffing: restrictions on taking on new staff, changes in the status of personnel, who are now employed on contract through government agencies or bureaux, or even sub-contracted through the private sector, thus

losing all guarantee of job stability or possibilities of a career in public services.

These measures have weakened, and even destroyed, government health services in some countries. They have prevented them from responding to the growing needs of their populations, whose demands have escalated as demographic pressure has increased, along with progress in education and health information. Instead of investing in health, they have disinvested in it.

The decentralisation of management and the integration of programmes and activities, based on attractive organigrammes, have been decided upon and carried out in a bureaucratic fashion: implemented without preparation or guidance, they have destroyed those programmes that were still functioning, without providing extra management resources and capacity for the intermediate levels which would have lent support to the activities of the peripheral health services. As a result, despite some local successes observed for example in Guinea or Mali, the MPA has not received the necessary prioritisation and support it needed; in some countries the national experts are still holding meetings to define the content of the MPA and to organise pilot studies on an experimental basis!

Cost recovery has been reduced to its most rudimentary - and most unjust - level: the poorest and most vulnerable population groups are forced to pay, while the privatisation of the medico-pharmaceutical sector has aggravated the social inequities between urban and rural areas, at the same time responding insufficiently and/or inappropriately to the demands of the urban population's small 'solvent' social group. The privatisation of drug supply networks has led to shortages and interruptions in the distribution of essential drugs, as seen in Algeria.

External aid has enabled some of the gaps to be narrowed, but it has also helped to increase dependence on the exterior, and compromised both the country's own appropriation of its priority health programmes and the possibility of long-term support. One can understand that the control of health expenditure has become a priority in high income countries, which spend between \$ 1.000 and \$ 3.000 US per capita per

year on health. However this goal cannot be adopted in middle income countries, where it is more a question of spending *better* than spending less. Furthermore, in even these countries the sums allocated to the public sector are sometimes insufficient. However, in the poorest low income countries, where public health expenditure comes to only \$ 2 - \$ 7 US per capita per year (whereas \$12 US would be necessary to apply the MPA), the idea of reducing the health costs is an act of aggression against the poor - an aggression which is rendered even more blatant when, given the circumstances, the experts congratulate themselves on the growth of private expenditure, presented as *the* alternative solution to the Providence State, although the transfer actually reflects the number of unmet health needs, the widening social chasms, and the misappropriation of households' financial resources by private health providers who are not quality controlled.

The recommendation, that the users should pay, has run into the wall of monetary poverty. Of the 5 billion human beings living in the developing world, 1.3 billion live under the poverty line and earn less than \$ 1 per day. The situation did not improve between 1987 and 1993, despite the structural adjustment programmes.

Elements of a more coherent approach

This is why a more coherent approach to problems related to health sector reform is now necessary. This approach would be based on the following:

- a better understanding, in each country, of the historic, political and socio-economic contexts of health services development and current reforms, as well as the level of local involvement in the reform process;
- an analysis of the real working of the existing health care system;
- lessons learnt from experience in other countries with the same socio-economic and revenue levels;
- the results of research directed more towards the process of reform than its content.

A more balanced definition of health sector reform has been proposed by Cassels, as 'a

sustained process of fundamental change in policy and institutional arrangements guided by the government, designed to improve the functioning and performance of the health sector and ultimately the health status of the population'.

The Impact of Health Sector Reform on Tuberculosis Control

One can already measure the impact of health sector reform on national tuberculosis programmes. The main elements of a well-run tuberculosis programme are well known:

- government commitment to guaranteeing financial support;
- case finding and tuberculosis treatment activities integrated into existing primary health services;
- permanent supplies of essential antituberculosis drugs and laboratory reagents;
- recording and reporting systems to ensure ongoing supervision and evaluation of the programme.

A programme such as this is not expensive to run - approximately \$1 US per capita per year in developing countries, depending on the drug regimens used, principally due to differences in salaries. However, if one calculates the cost of specific expenditure in an integrated programme, the total necessary investment costs (microscopy laboratories, means of transport) and running costs (drugs, laboratory reagents, logistics and maintenance, training and supervision) come to about \$ 0.10 - \$ 0.30 US per capita per year, half of which goes towards antituberculosis drugs.

The cost of antituberculosis drugs is no longer an obstacle to the application of a modern, efficient programme, nor to the use of short-course chemotherapy regimens for all patients. If one excludes the poorest countries, in the majority of developing countries the supply of antituberculosis drugs can come to less than \$ 0.10 US per capita per year: more exactly \$ 0.03 - 0.09, depending on the number of cases detected. Unfortunately, the rapid implementation of health sector reform has had a negative impact on tuberculosis control in several African countries. Its integration, inadequately understood and applied, has had the following consequences:

- the dilution, or even the disappearance, of the programme's central unit and/or its own specific budget;
- the 'integration' of antituberculosis drug supplies into pharmaceutical supply systems that are defective, inefficient and irresponsible;
- bureaucratic conflicts with those in charge of general health information systems;
- arbitrary cuts in the numbers of hospital beds available for tuberculosis patients, with no redistribution of human and financial resources, and no previous or parallel improvements in the conditions for ambulatory treatment of patients.

Nevertheless, well-understood reform could reinforce tuberculosis control, on the following conditions:

- awareness activities targeted at decision-makers at all levels, central and local, should be reinforced;
- the costs of the programme should be shared by the central State budget and that of local government or municipal authorities;
- the costs of personnel training and supervision should be shared by other programmes (leprosy, lung disease); the costs of antituberculosis drugs could even be shared by the AIDS programme, as in certain African countries 40-50% of tuberculosis patients are HIV seropositive;
- control should be maintained of the antituberculosis drug supply network, even in an effective integrated system of drug supply and distribution;
- quality control of the network of microscopy laboratories should be organised from a central national reference laboratory (or regional laboratory in countries with a large surface area), which should also be integrated into a national public health laboratory (Table 9);
- the information system specific to the programme should be safeguarded, allowing surveillance and evaluation of the programme's performance to continue, at the same time continuing to provide valid epidemiological data for the general health information system.

These basic principles do not suffice. Well-understood reform must above all answer to

the needs of the population. This is why it should above all reinforce the management and technical support capacity of teams situated at the intermediate level (province or region) in order to guarantee that at the periphery, patients have access to a fully equipped laboratory, run by qualified and supervised personnel, situated less than 20 km from their place of residence; receive free essential antituberculosis medication and free follow-up examinations during treatment; have access to a regular supply of the drugs that they need; and are received and treated by health personnel who are well trained, regularly paid and supervised, and fully accountable. These conditions are not a theoretical outline: they can be found in many districts in African countries as distinct as Morocco or Guinea, Djibouti or Mali.

In fact, even if health sector reform has dismantled or weakened the national tuberculosis programme, one must look elsewhere for the real causes of the poor impact of the tuberculosis control strategy, including the strategy recommended by the World Health Organisation (WHO). It is true that short-course, directly observed treatment improves treatment results. However the impact of its success is limited in many developing countries by the low health coverage of the population (less than 50% in many African countries); the allocation of insufficient sums to specific activities of the national tuberculosis programme, particularly training and supervision; and above all, by the priority given to cases of smear negative tuberculosis or cases for whom no microscopy is performed, based on the decision of doctors who still prefer X-rays to laboratory examinations for diagnosing tuberculosis. Not only are the sources of infection detected inadequately, but precious, available antituberculosis drugs are distributed in priority to individuals who are not sources of infection.

As a result, cases of smear-negative pulmonary tuberculosis, who should normally represent 15-25% of pulmonary tuberculosis cases in some efficient tuberculosis programmes (as in Djibouti, Guinea, Mali, Morocco, Algeria, Vietnam or Peru), can constitute 50-85% of the pulmonary tuberculosis cases who are identified, notified and treated (as in the

Philippines, China and Pakistan). Several reasons can be identified to explain both these results and the erroneous choice of priorities. However, the principal reason is the neglect of adult respiratory diseases other than tuberculosis by health workers.

If health sector reform was centred on the highest priority respiratory diseases in the population, the most common respiratory diseases could be controlled. If one situates tuberculosis prevalence, at about 7-8 million new cases per year, in the general framework of lung diseases, one can observe that tuberculosis is less frequent than acute respiratory infections (ARI - 394 million cases), chronic obstructive pulmonary disease (COPD - 600 million cases) and asthma (275 million cases). This distribution can also be found on a national level: in a middle-income country such as Algeria, at each level of the health services tuberculosis represents only a fraction of lung disease in general.

World wide, tuberculosis and other lung diseases represent 19% of all morbidity, i.e., the number of years of active life lost (disability-adjusted life years, or DALYs); in sub-Saharan Africa and south-east Asia they represent 23%. In most developing countries, respiratory symptoms are the first or second reason for patients presenting at the health services: 17% in Mali, and 38% in Djibouti. Among patients who present with respiratory symptoms, 10-20% are suspected of having tuberculosis, and smear positive pulmonary tuberculosis cases represent only 1-2% of the total of symptomatic patients.

Therefore, if one wishes to precisely identify cases of infectious tuberculosis, it is important to respond appropriately to the needs of patients with respiratory symptoms but who are not tuberculosis suspects, and also to the needs of those who are tuberculosis suspects but who have persistently negative smear examinations: these two groups of patients represent 98-99% of all individuals presenting with respiratory symptoms.

As has been observed in the Ivory Coast, this demand for treatment of respiratory symptoms is included among other demands for other general symptoms - digestive, nervous, skin, and genital. We must therefore first of all find

a solution to this problem, before imagining further integration or concerted management of other vertical programmes (such as STD and AIDS programmes). In the framework of the MPA, functional integration - based on symptoms - seems the most natural approach.

When applied to respiratory disease, the symptomatic approach to health care has three advantages:

- it responds to the needs and expectations of the patients;
- it can easily be integrated into the MPA recommended in each country;
- it represents the main port of entry into the community health services for the management of respiratory symptoms - including pulmonary tuberculosis.

This method does not aim to create a new vertical programme that is broader than the previous one. It aims at codifying the empirical approach adopted by health personnel (often at a high price in wealthy countries, or at an unaffordable price in poor countries). It simply requires that explicit, rational and realistic decision-making algorithms be defined and applied that can be used in any type of situation and be adapted to the level of competence of the health personnel. It integrates the management of ARI in adolescents, adults and the elderly (whatever the prevalence of AIDS in the country concerned), and that of the most frequent chronic lung diseases (asthma and chronic bronchitis) by the appropriate use of drugs - antibiotics, bronchodilators and corticosteroids - to treat symptoms.

The notion of adopting a symptomatic approach to lung diseases, abandoning the old vertical approach, limited to a single disease, has a number of important implications. This change opens up new perspectives for further change: Fundamental changes in forming health personnel, whether in medical or paramedical schools or in in-service training. It requires the implementation of a programme and teaching methods oriented towards solving the patients' problems, rather than the pseudo-encyclopaedic rote learning of a catalogue of illnesses.

Changes in operational research, which could aim, among other things, at finding new,

appropriate indicators for ensuring that the most common lung health problems are adequately monitored, and at choosing the most efficient technical or educational measures to resolve problems in each country's specific context. In this general framework, international scientific Cupertino could play an important role if it took place in conjunction with (and not at the expense of) the patients and health personnel of developing countries.

According to the still limited experience acquired in a few countries in Latin America and Africa, the respiratory symptoms approach is of interest because it responds to the broad, consensual objectives of health sector reform. It improves the quality of care, the competence of the health personnel, the confidence of the population at large in care-providers, equity in the delivery of basic care (by limiting unnecessary travel, referral appointments and supplementary tests), and the efficiency of the care delivered for lung diseases and tuberculosis.

Conclusion

Beyond health sector reform, reforms are taking place that will have an impact on health. These reforms can be an opportunity to improve tuberculosis control and the management of lung diseases, particularly in the developing world.

The promotion of lung health is a collective responsibility, shared by the state, the population and the health professionals of each country. For the health professionals involved in tuberculosis and lung diseases, this responsibility is particularly burdensome. Between the World Bank and Mother Theresa, there is a whole social space to fill in order to organise, and if necessary invent, new institutional forms of national solidarity and international co-operation, so that we can prepare a world in which our children and our grandchildren will be able to breathe.

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WHO RESEARCH PROJECT OF THE COMMUNITY CONTRIBUTION TO EFFECTIVE TUBERCULOSIS CARE IN AFRICA

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Background

The HIV-fuelled Tuberculosis (TB) epidemic in sub-Saharan Africa is outstripping the ability of health services to cope. National TB Programmes (NTPs) face the challenge of improving access to diagnosis and treatment and assuring effective treatment and cure. Decentralising the provision of TB care beyond health facilities and into the community has the potential to overcome some of the limitations of reliance on health facilities in facing the challenge.

The project "Community TB Care in Africa" aims to evaluate the community contribution to effective TB control, as part of NTP activities, in high HIV prevalence countries. Evaluation outcomes are acceptability, effectiveness, affordability and cost-effectiveness. If successful, the project will generate policy guidelines for Ministries of Health and NGOs on how NTPs and communities can work together to ensure successful treatment of patients. WHO is leading and co-ordinating this collaborative project, with funding in the first year of the project from USAID via CDC and technical support from CDC, USAID, KNCV, IUATLD, and UNAIDS.

Methods

Eight district-based projects are underway in 6 countries: Botswana, Kenya, Malawi, South Africa, Uganda, Zambia. Countries started to implement their protocols at different time in 1998 and are collecting relevant data for TB cohort, economic and socio-behavioral analyses. The methodology in each project is to compare outcomes in a system where TB care is available only through health facilities with a system where patients have the additional option of treatment in the community. The outcomes are TB case-finding and treatment outcomes, cost-effectiveness and acceptability.

Results

The overall project began in late 1996 with mobilisation of funding and identification of sites and investigators. The countries with district-based community TB care interventions under way as part of the overall project are: Botswana (project funded separately by CDC), Kenya, Malawi, South Africa (Guguletu), Uganda (Kampala and Kiboga) and Zambia. These district-based projects provide patients with the option of community TB care, within programmes implementing the internationally recommended strategy for TB control. The individual projects began at different times in 1998 and will run for 2-3 years. Investigators have completed a situation analysis in each of the following 3 sites, preparatory to a proposed intervention: Rundu District, Namibia; Hlabisa, South Africa; Kilombero District, Tanzania (which falls outside the main umbrella project but has received technical support from WHO).

The different district-based projects have made variable progress in successfully making available the option of TB treatment in the community, and assessing its acceptability, effectiveness, affordability and cost-effectiveness. The project in Francistown (Botswana) is at an early stage of making the community TB treatment option available. The project in Kampala (Uganda) has not yet succeeded in decentralising the provision of TB care to make full use of existing health facilities and in identifying and mobilising CHWs. The project in Ndola (Zambia) has integrated the provision of TB treatment with an existing HIV/AIDS community care scheme, with up to now quite small numbers of TB patients treated in the community successfully.

The project in Lilongwe (Malawi) has successfully decentralised the provision of TB care using many health facilities in the district, and made widely available the option of community TB treatment to patients with sputum smear-negative pulmonary TB. The projects in Machakos (Kenya), Guguletu (South Africa) and Kiboga (Uganda) have successfully made the option of community TB treatment widely available in the respective districts, with generally satisfactory rates of treatment success. The indications at this interim stage are that the option of community TB treatment is acceptable and affordable (from the point of view of both the patients and the health care provider). Evaluation of cost-effectiveness will provide powerful evidence for policy-makers, if the evaluation shows that providing the option of community TB treatment is not only effective, acceptable, and affordable, but also cost-effective.

Successful collaboration among the general health services, NTP and CHWs is crucial and depends on the following: i) good communication links and referral scheme; ii) good education of the TB patient and the patient's family; iii) training of the Community Health Workers (CHW) and the health services' staff; iv) system of regular supervision of CHWs by NTP and general health services' staff. The main challenges include the identification of the leadership responsible for managing the process of introducing the community TB treatment option, development of management capacity and ensuring sustainability.

The projects in Rundu (Namibia), Hlabisa (South Africa) and Kilombero (Tanzania) need to move on to the implementation of

community TB treatment, using the results of their situation analyses. The projects in Francistown (Botswana), Kampala (Uganda) and Ndola (Zambia) need to review the reasons for, respectively, a slow start, limited uptake of the community TB treatment option, and limited case registration. The NTP staff involved in the projects in Lilongwe (Malawi), Machakos (Kenya), Guguletu (South Africa) and Kiboga (Uganda) face the challenges of demonstrating sustainability after the end of the "special project" phase, and of spearheading the extension of a successful approach more widely.

Conclusions

The interim indication is that the option of community contribution to TB treatment is effective and acceptable where there is successful collaboration between the general health services, NTP and community health organisations. The final project results will be available in the year 2000 and the results of the evaluation of effectiveness, acceptability and cost-effectiveness will provide powerful evidence to guide policy-makers in recommending the option of community TB treatment.

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SOCIO-CULTURAL ASPECTS OF CHRONIC INFECTIOUS DISEASE: TB, AIDS, LEPROSY

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Tuberculosis is drastically increasing in areas with high HIV prevalence. In countries of sub-Saharan Africa, such as Zimbabwe, Zambia, Kenya, Malawi, where TB was reasonably under control in the mid 1980s, the number of registered TB cases has trebled or quadrupled during the past ten years. This increase has not only serious consequences for the health services. It also negatively influences community perceptions on TB. Whereas the disease had been gradually destigmatised over the past 25 years thanks to the fact that effective medicines are available to cure TB patients in six to eight months, the present increase of TB, in many cases fatal due to co-infection with HIV, has revived the stigma. Community members often do not clearly differentiate between TB and AIDS; to them TB is back, stronger and more frightening than before. Leprosy, on the other hand, is gradually loosing some of its terrifying image as prevalences go down.

Definition of stigma

How can we define stigma, and what determines it? Goffman (1966) defines stigma as an attribute, an undesirable differentness that discredits or disqualifies the individual from full social acceptance. This undesirable differentness can be physical or social, or both. The concept derives from the brand (called stigma) with which the ancient Greek used to mark their slaves.

Manifestation of stigma

Diseases which are characterised by visible, fear provoking signs and perceptions of infectiousness and incurability/death are particularly prone to stigma. In many societies, TB, leprosy and AIDS share these characteristics or did so in the recent past. The most powerful defence which community

members have against such diseases are the avoidance and isolation of patients.

Avoidance can take many forms and occurs at different levels: at community level (including work and recreation), at the level of spouse and in-laws, among (blood) relatives, and even through auto-stigmatisation by the patient him/herself occurs. Patients may anticipate stigma when they notice signs of a stigmatised disease or hear the diagnosis. They then withdraw from social life even when stigmatising signals from the community are absent or weak.

In Jos, Northern Nigeria, a young man stifled when he heard the diagnosis of leprosy (litt.: dropping off of fingers and toes) and from then onwards remained mostly inside. Neighbours who had noticed the swellings in his face but had not avoided him, now also kept a distance and greeted him merely from the door. When the swellings subsided after three months of treatment, the patient relaxed and social relations went back to normal.

A middle-aged woman in Aceh, upon hearing the diagnosis of leprosy and being afraid of a divorce, proposed to her husband to marry a second wife. The husband, considering his wife had born him enough children, refused even after his wife had mobilised her sister to convince him; they stayed together as usual. The opposite occurs as well, perhaps more frequently. Then, community members start to avoid contact with a patient even before a diagnosis has been made or when the patient is aware of it but tries by all means to cover up the symptoms.

At these different levels, stigma expresses itself as a continuum: from zero or minimal to maximal strength. At community level, for example, stigma may start as gossip; those who can afford it (not related, not befriended with

the patient) may start to keep some distance. When signs become more visible and suspect, outsiders may more ostentatively refuse to share food, water, beer with a patient. As the disease progresses, neighbours may become hesitant to enter a patient's house, don't shake hands any more, will not share food or drinks, but may, if they are on good terms, still render services (draw water, for example). A public sign of disrespect at this stage may be that children tease a patient and call him names ('leper!') without being rebuked by parents or other adults. Finally, maximal stigma equals social death. Patients are forced to live at the outskirts of the village, they are no longer allowed to enter the mosque, or are expelled from the village in the expectation that leprosaria or TB sanatoria will care for them. (Many community members still complain that these institutions were closed; in countries where HIV is highly prevalent a common first reaction was that the government should isolate patients in jail). Before treatment for TB and leprosy became available, relatives would build a hut for a patient close to the river and bring him/her food daily. In extreme cases, patients would be killed, e.g. thrown from a rock. In case of leprosy, this would never occur before serious visible signs appeared. In the case of TB and AIDS, patients in the final stage of disease are so sick that they remain inside anyway. Whereas normally the seriously sick get extra social attention and burials are important social occasions, this may be different with respect to persons suffering from stigmatised diseases. The worst example of isolation I heard in Zimbabwe was the refusal of community members to attend the burial of an AIDS patient: clearly, physical death equalled social death.

Such extremes are and may always have been exceptions. There are counter forces in society that mitigate stigma. Parents do not easily drop a child, children, especially daughters, do not easily drop a parent, though some separation may occur, especially if the condition seems permanent or is worsening. Husband/wife relationships are more fragile as these relationships can be dissolved. Serious, irreversible chronic disease is like infertility, in many cultures a ground for divorce or, for men, to take a second wife if religion allows (and even if it does not...).

A first manifestation of stigma in marriage is the non-sharing of food, drinks and bed. Then a more drastic form of separation may follow, e.g. a (temporary) of one partner to his/her relatives. When symptoms do not diminish, divorce may be a final step. However, the stigmatisation process is not always that gradual.

In the rural environment of Jos, a 60 year old woman was diagnosed having a lighter form of leprosy. When she told the news to her husband, he exclaimed: "What, you are bringing such a bad disease to the house! There is the gate!" She went to live with her son and managed to scramble the bus fare for her monthly treatment together by preparing and selling snacks. When we interviewed her one year later, she had been declared cured. Ironically, her husband had died in the meantime. Mutilated ex-patients who had formed a mutual support group in Jos (begging being their main source of income) declared that the behaviour of this husband had been quite exceptional. Their spouses had waited 'long enough' and had only left them when the situation kept deteriorating.

When the disease started, 20 years ago, a male leprosy patient in Aceh, Indonesia had been spotted by community members. He had left by himself, turned to fishing to maintain his family and in the mean time took traditional treatment in the hope that the symptoms would disappear. After three years he returned without being improved, and decided to build a shelter on his fields where he would stay all by himself. He could still cultivate rice and maintain his family; his sons sometimes came to assist him but he never returned to the village, except sometimes at night to see his family. He recently started treatment which the leprosy worker, alerted by village elders, brings him. The leprosy marks in his face are unmistakable, but not frightening. However, he has been so hurt by the behaviour of the villagers that he hesitates to go back.

Often, in-laws (parents of the healthy spouse) propose divorce long before the spouse him/herself would think of it. Why this reluctance? Women loose socio-economic security, and, more seriously, in patrilineal societies where descent follows the male line, they will loose their children. Men may resent

divorce because their wife has born them enough children, when she fulfils her domestic and economic tasks despite the disease, and/or when the relationship between partners is good. A bad marriage is prone to quick divorce when chronic stigmatising disease appears. But stable marriages usually remain in tact.

However, relatives and spouses who remain loyal to a patient with a potentially stigmatising disease pay a price. When community members become aware of the disease, the patient's close relatives may share in the stigma, the avoidance. The search for a suitable marriage partner includes the question whether 'bad diseases' run in the family of potential in-laws. Moreover partners and close relatives share the community beliefs on infectiousness and have to suppress fears. Caretakers need therefore counselling and support as much as patients do, as part of those fears may be exaggerated.

Discrepancy between expected and experienced stigma

Upon hearing the diagnosis of a bad disease, whether TB, HIV/AIDS or leprosy, the first expectations are usually death, divorce and social isolation. Community experience is selective: only advanced disease becomes visible and the worst examples of stigma are memorised and become stereotypes. Local terms for the disease usually refer to advanced forms (big cough, slimming disease, loss of hands and feet) which reinforces the fear. In reality a wide scale of stigma will appear, from zero to some form of isolation, but most patients experience to their relief that the reality in terms of disease outcome and stigma is far less bad than they feared.

For TB and leprosy this discrepancy is predictable: both diseases are curable nowadays, and some 80-85% of leprosy patients neither have nor develop deformities, often to their own surprise. In Egypt, some newly diagnosed TB patients revealed their initial fears: apart from death, males were particularly afraid that they would no longer be able to care for their family, which is shameful, that they would loose the respect of the community and be avoided; women above all feared divorce. In most cases, family members (brothers, even the wife who adopted some of

her husband's economic tasks) helped out till the patient could resume his duties, though one man complained that his coffee shop had lost customers. Most wives experienced that their husbands still visited them in hospital but a young woman's engagement broke up. One young mother was so determined to leave the hospital prematurely for fear of losing her husband that she was one of the first Egyptian patients put on DOTS.

With respect to HIV/AIDS and TB in HIV-endemic areas, fear of death and stigma are much more justified, but overreacting may unnecessarily aggravate the patient's suffering. The equation of TB and AIDS, e.g. may demotivate TB patients to take treatment which could prolong their life. All patients suffering from stigmatising diseases require careful counselling to reduce fear, but regarding HIV, this is most delicate and challenging for staff.

Coping mechanisms and risk groups

A strong social network, availability of economic resources, high social status, improvement of signs and symptoms through regular treatment (TB, leprosy), favourable personal characteristics (beauty, intelligence and creativity, kindness, religious faith and strength to accept) are all positive conditions for coping with stigmatising diseases when hiding is not fully or no longer possible.

Adolescents of both sexes are a major risk group, as they have not yet settled, neither socially (marriage) nor economically. Young leprosy, TB and HIV+ patients alike fear that the disease threatens their chances for marriage. Though their fears are sometimes justified, especially if they have meagre social and economic resources, most cope if their health allows:

In Aceh, a young woman, literate and apparently beautiful, was already engaged when some persistent patches on her skin appeared to be leprosy. Her worried fiancé (Moslem and already married) consulted the leprosy worker asking whether the disease could be cured and whether it would interfere in any way with the girl's child bearing capacity. The leprosy worker reassured him, but he still waited three months, till the patches

had subsided, before the marriage was arranged.

It is difficult to say whether men or women cope better with these stigmatising diseases. Women in general have less resources than men, but they tend to handle their resources more carefully, report earlier for treatment than men and usually comply better with prescribed medication.

In societies with a strong preference for boys (S+ E Asia, Middle East), however, girls appear at a disadvantage; boys are better fed and receive more prompt medical care in case of disease. Older women with stigmatising diseases may likewise be more at risk than older men to remain untreated and end in isolation.

Some community perceptions about possible causes of stigmatising diseases may work against patients: punishment of God for sin committed in a previous or present life (leprosy, Nepal; (less: Aceh)), promiscuity/trespassing of sexual taboos (seen as a cause of HIV as well as (though less) of TB and leprosy in most research areas) These beliefs create a double stigma for the patient, as (s)he is believed to deserve the disease. Especially women are hit hard by the accusation of sexual looseness, as in many if not all societies sexual norms are much stricter for females than for males. Even parents may withdraw from a HIV positive adolescent or turn angry because of the double shame brought to the family. Adults can cope better than adolescents with such accusations by putting the blame on others (witchcraft is a possible explanation for any misfortune). For leprosy and TB there are many plausible less 'stigmatising' causes than sexual misconduct.

It is unfortunate that chronic diseases involve costs for the family which put a heavy strain on the very resources that should enable them to cope with the disease. Reduction of income due to temporary or even permanent incapability to work, costs of treatment and travel, may drain the already meagre family resources. HIV/AIDS in particular is a heavy burden to families because it predominantly attacks the productive age groups which have to raise the next generation and -as social security systems in developing countries

hardly exist- to take care of the elderly. Treatments sought are usually devouring money, but ineffective. HIV-infected mothers may have to care for sickly children, to whom they unknowingly transmitted the infection, and often for HIV-infected husbands as well. Here HIV implies that many families are trapped in a downward spiral towards absolute poverty. Extended families who customarily take care of children in case one or both parents die, are confronted with an unprecedented number of orphans which equalling catastrophes like war and famine. New coping mechanisms have to be developed when existing fail. Institutional care seems least preferable, as it dissolves children from whatever support their local environment offers and is too costly to cover all in need. New forms of households emerge, child- , grandparent- or foster parent headed. Prospects for school education of these orphans are dim, unless the government and NGOs assist, and the number of street children is increasing in African towns which did not face such problems ten years ago. Less visible but not to be mistaken is the influence of AIDS on the national economy as more and more adults in the productive age group get sick and die.

Possible measures to increase cure rates, decrease stigma and provide additional support (In respect to TB, leprosy; for HIV/AIDS: to prolong life expectancy). Stigmatising infectious diseases form a special challenge for health facilities, as staff is usually as afraid of these diseases as any other community member. Special interactive training of staff is required to reduce such fears to realistic proportions. It is astonishing how little health staff is aware of the rapid effect of leprosy and TB treatment on infectiousness, and even if they have had special training, how little they exploit this knowledge to take away the fear of infection among community members and relatives which is a major source of stigma. Rendering a patient non-infective is the strongest advantage of biomedicine; as the prospect of cure after regular TB/leprosy treatment only partly coincides with patient expectations. Patients -like relatives and community members- expect that all symptoms of leprosy and TB will disappear, also irreversible damage, and it requires a special effort to explain the strengths and limitations of treatment in respect to cure. Also

the duration of treatment is not always told to patients, which is crucial information to enable them to organise their lives and obtain assistance, where necessary. As the delays in reporting of TB and leprosy are still considerable, in Aceh and Nepal on average 3-5 years for leprosy, and case-holding could still improve intensification of IEC is a must, not only to control the disease but also to diminish its social and economic consequences.

For HIV/AIDS and HIV-related TB the challenge to the health services is even bigger, because infection can only be prevented, not cured. Additional opportunistic infections confuse the patient as treatment may improve his situation, whereas he had expected death. Staff is confronted with the dilemma of confidentiality vis à vis the patient versus the duty to protect partners when the patient apparently does not inform them. It is not surprising that services do an appeal to community members to assist in IEC, help support patients and their relatives, and in particular orphans. NGO support groups are mushrooming all over sub-Saharan Africa. NGOs are pioneers as well in promoting adolescent sexual and reproductive health through interactive peer approaches. Public health services are generally less strong in participatory, community based approaches than NGOs, but sometimes they co-operate with volunteer counselling groups (Zimbabwe, AIDS), or they attempt to involve ex-TB or -leprosy patients in providing health education to the community or to new patients (India, Nepal, Nigeria, Aceh/Indonesia). Such support is essential as new patients usually remember little from information provided at the time of diagnosis; they need time to first digest the bad news. Also relatives/caretakers, who often have at least as many fears and worries as the patient, benefit from such services, which most likely helps motivate the patient to cope with the disease and prescribed curative/preventive behaviour. (evaluation is necessary)

The following measures could therefore be taken by health service:

- interactive training of staff responsible for care of TB/leprosy/HIV/AIDS patients
- in order to reduce unnecessary fears and teach them 'learning by doing' the interactive approach required for IEC to

patients, their relatives and community members on sensitive diseases.

- sound IEC to community members, on symptoms of TB and (if prevalent) leprosy, available treatment and its favourable impact on infectiousness and cure
- repeated interactive counselling of patients and their caretakers/trusted relatives
- careful selection and training of peer educators among (ex)-patients (being aware of inter-patient stigmatisation as well as possible fear to come out in the open) or their relatives, adolescents and other possible target groups (e.g. working place)
- life sessions on TV, e.g. interviews with cured TB/leprosy patients and their spouses on their own disease history (symptoms, different treatments sought, (non) experienced stigma, cure, present integration in society) to give examples of successful coping, peer education sessions on safe sexual behaviour, activities of home-based care support groups for HIV and other chronic patients. If possible: life stories of coping HIV+ persons (M/F; rural/urban; educated/less-educated) so that everyone can identify with the broadcast
- needs assessment of vulnerable groups related to HIV/TB/leprosy (orphans, adolescents, female-headed households, those below poverty line) assessment of possible local resources and mutual support, of possibilities of additional external support.

In Europe, TB incidence is also increasing as a consequence of increased mobility and immigration from areas where it is still a problem. It is still a feared, and sometimes stigmatised disease. Stigma on TB in Europe is based on stereotypes of the WWII period and late '40s, when the disease had flared up and treatment was still rather ineffective. Till today, stigma is reinforced by incidental alarming reports in the media about small explosions of TB (confusion of infections with actual disease). Without additional information on treatment and cure. Such reports raise fear of infectiousness

Stigma occurs in both Europeans and immigrants, but due to their low social status,

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immigrants are more vulnerable. HIV/AIDS in Western Europe is presently mainly confined to homosexuals and intravenous drugs. Due to in-and-out mobility to HIV-infected areas of autochthonous as well as immigrant groups, an increase of heterosexually transmitted HIV in Western European towns is one of the greatest risks for stereotyped stigmatisation and discrimination of immigrants. Intensive IEC projects with educators of different ethnic groups and surveys to monitor HIV prevalence are ongoing, e.g. in Amsterdam but we could learn from the innovative and participatory IEC approaches that are experimented with in countries where stigmatising chronic infectious diseases are highly prevalent.

NB Examples are drawn from still unpublished 'gender and leprosy' research carried out by

health staff and social researchers in Aceh, Indonesia, Northern Nigeria, Nepal and Brazil, by TB/health staff in Egypt, and by a HIV counselling team in Buluwayo (Meursing, K 'A World of Silence', Royal Tropical Institute, Amsterdam, 1997)

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ETHICAL ISSUES IN THE TREATMENT OF TUBERCULOSIS

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Introduction

I must warn you that my comments will not fit into most of the categories that are described for this talk in your program. As I have thought about this presentation for the last several months and as I listened to what I thought was a very dynamic and exciting day yesterday, my reflections have settled down into one large thought and two small ones.

To introduce the major consideration, I would like to first set the stage by discussing what I believe are two major themes in our ethical tradition which have contributed to our manner of proceeding and then reflect as well on our psychological and emotional makeup as we approach these questions. The two principles are gradualism and the toleration or counselling of lesser evil; the psychological perspective is that of heroic generosity.

Toleration and Heroic Generosity

Our mandate to care does not come from government, but from the biblical injunction to love one another. At the same time, our ministries may be financed by groups and structures which are overwhelmed by competing demands for services and at times they may only be able to provide support on an intermittent basis due to competition for scarce resources. Many of you work in situations in which the health-care structure may be interrupted by political instability, by changing commitments of donor agencies and even by discord within the organisation for what the appropriate prioritisation of limited resources should be.

The principle of gradualism which has been developed especially in the area of individual pastoral care is based upon the recognition that as humans we are always in process as we grow toward greater holiness, maturity and

personal integration. Especially for the individual who faces enormous struggles and challenges, such as those with addictions, we recognise that movement toward what we may identify as an ultimate goal cannot usually be accomplished in a single, giant step, but can only occur in many smaller steps over time. Thus from a psychological and spiritual perspective the principle of gradualism supports our encouraging those in our care to take whatever next small step is possible as they move toward a larger, long-term goal.

Case Study of Gradualism: Drug Addiction

My own medical work is based in an inner city hospital AIDS clinic in Boston in which the majority of persons have become HIV-infected from sharing of contaminated needles during injection of drugs. Thus, addiction to drugs, alcohol or both is frequently the context in which patients are struggling to cope with their HIV infection. Relapse into active drug use is common, especially as stresses from HIV disease increase and thus we try to focus on helping individuals to take small concrete steps toward recovery, one day at a time. Practically speaking, this means that of course we encourage individuals to abstain from drug injection and we recognise that this may only be possible not by asking them to imagine a drug free future, but only to concentrate on getting through today or even through the next hour. And of course it means we recognise that relapse is a characteristic of the disease we know as addiction and thus our educational efforts include encouragement toward abstinence, but also toward minimising harm if abstinence is not possible.

That means we tell patients that if they are not able to abstain from injection, we encourage them to access a needle exchange program to obtain a sterile set of injection equipment. If this is not possible, then we educate them about cleaning their used needle and syringe with bleach, just to make sure that their drug relapse does not lead to transmission of HIV as well. As an aside, I would say that while I recognise that contaminated injection represents a very small proportion of HIV transmission in the world at large, it now accounts for nearly half of new infections in the United States. I am sure you can imagine how efforts to convince church officials to

support needle exchange is a replay of the entire condom debate that we have been struggling with for years.

Counselling or Tolerating the Lesser Evil

I have mentioned gradualism. The Catholic ethical tradition has also developed the principle of counselling or tolerating the lesser evil as one of its unique contributions to moral reasoning. One of the early proponents of this model was the Redemptorist Alphonsus Liguori, an 18th century bishop whose moral theology was strongly influenced by his extensive experience as a pastoral counsellor and confessor. Alphonsus was faced at the level of ethical analysis with the question of whether it was permissible to support an activity that is admittedly morally wrong if doing so could avoid an even more gravely wrong activity which its perpetrator was committed to performing despite all counsel. For example, Alphonsus argued that it is not wrong to counsel someone who is intent on killing another to limit his or her aggression to striking or beating.¹

One of the earliest precursors of this principle in the fifth century may have been the advice of St. Augustine to tolerate the establishment of houses of prostitution in Rome. Augustine recognised that the presence of prostitution in human society was unlikely to be eradicated and he was concerned with minimising the harm that might result. Thus he felt that rather than fight unproductively against prostitution, it was better to allow the establishment of brothels in order to minimise safety risks. This of course was a precursor toward arguments supporting the legalisation and regulation of prostitution and might be seen as a forebear to the legalisation of certain kinds of drug use to prevent their association with organised crime and enormous black markets. I have argued that this is the same principle that should motivate the church not just to tolerate, but to actively promote needle exchange programs in order to prevent the loss of life that comes from HIV transmission among injectors and from secondary transmission to sexual partners and, in the case of women, to developing foetuses or to breastfeeding infants.

Our Grounding in doing "What is Possible"

My reason for discussing these two principles of gradualism and toleration of the lesser evil is to point out that we are trained in the art of doing what is possible, of recognising that all the resources that we would like to have at hand may not be there and under such circumstances we do what we can, often flying by the seat of our pants. From this perspective we recognise that at least giving someone a piece of bread is better than not being able to give them anything at all, that providing pain relief and simple measures of hygiene may not save someone's life but they can provide a dignified setting in which to die.

It has also been my experience that we who are members of religious communities or who are health care professionals at least in some degree can tend toward aspiring to heroic generosity. We may also have just a touch of the rescuer in our psychological make-up. These are not necessarily bad things, but in excess they can become neurotic and self-destructive and must be tempered by reasonableness. Of course as someone who is both a religious and a health care worker -- and I know there are many of us in this room -- I wonder if that means we are in for a double dose of trouble! My point is that we are conditioned and intrinsically motivated toward extraordinary generosity. In the words of a prayer that has been attributed to St. Ignatius but in my understanding was actually something of a romantic and perhaps slightly neurotic revision from the Renaissance, we are encouraged "to toil without counting the cost, to fight without heeding the wounds." As part of this generosity we are conditioned to do whatever is possible, even though that may not be very much.

As we face conditions of extreme poverty and hunger, we may not be able to offer a banquet or a full wardrobe, but if we can provide rice or flour or cooking oil or a high protein supplement or a blanket or a jacket, we know that we have at least done some little good that will promote survival and comfort.

But one of the most important things which I believe was pointed out to us yesterday is that as we approach the complicated issue of treatment of TB, especially in the context of HIV infection, this concept of doing the best

that we are able to do -- even though that may not be very much -- may actually cause us to do harm.

Professor Grosset alluded to the United States' history with multidrug-resistant Tuberculosis (TB). It is true that this phenomenon has not yet been replicated in other parts of the world, but I know of no reason why the U.S. experience should not be considered a harbinger of what could happen in any location in the world in which TB Control Programs are poorly administered. In fact, we know that TB cases and drug resistance are expanding rapidly in the former countries of the Soviet Union and perhaps it is there that this phenomenon will next be replicated.

Very briefly described, TB cases had been declining in the United States steadily over a number of years and consequently the city of New York gradually diminished resources to administer its TB program. Subsequently, the number of patients who did not complete therapy rose dramatically and as a result we witnessed several outbreaks of TB that was resistant to two or even three or more drugs: MDR-TB, especially in the context of congregate care such as hospitals and prisons. This occurred first in New York City, but was subsequently seen again in the state of Florida.

This is not a small issue. These multidrug-resistant outbreaks had a 40-60 percent mortality in immunocompetent persons with the best treatment and more than 80 percent among persons who were HIV-infected. In some cases the time from diagnosis to death ranged from 4-12 weeks. Treatment of these patients required prolonged hospitalisations at an average cost that has been estimated to be close to one million dollars.

Although it is true that multidrug-resistant organisms are not more contagious than susceptible bacilli, we do know that HIV-infected patients who are immunocompromised are not only more vulnerable to reactivation of latent infection, but are also exquisitely susceptible to developing active disease soon after exposure. Some of these outbreaks spread rapidly through AIDS clinics as people waited to see their doctors, or as they were hospitalised or incarcerated in prison cells. In some instances,

HIV infected nursing personnel who became infected succumbed rapidly. This scenario of course could be repeated in scores and scores of HIV programs around the world.

The Tempering of Generosity and Charity

The point is that our generosity and zeal to do something must be tempered - as referred to by many public health experts yesterday - by a consideration of the impact of our efforts not just on an individual, but on the common good and the public health. We know that giving a very short course of therapy against TB can lead to a reduction in symptoms quite quickly and of course this is one of the problems that leads to non-completion of therapy: people who feel well have no motivation to continue taking pills. Our classic desire to care for the individual who is suffering would of course lead us to want to minimise that suffering by offering any therapy that we could, but now the stakes have changed dramatically. For the first time, we may need to consider that, unless we have the infrastructural capacity to guarantee 6-8 months of uninterrupted therapy, it may be better for us not to treat at all. We have been trained that something is better than nothing, but in this circumstance we are shocked to realise that nothing is better than something. Even though brief but incomplete treatment may benefit an individual at least temporarily, in the long run if we are really concerned about the community, non-treatment of TB is better than inadequate treatment.

The Contract Approach

We have been trained toward generosity, toward doing anything we can to help the suffering. But perhaps the ethical and even spiritual lesson that we have to learn from HIV and TB is not generosity, but humility: to recognise our poverty if our resources are not adequate and to face the difficult ethical question of withholding therapy unless and until donors and partners can guarantee the structure to complete therapy. Yesterday our colleague from Cambodia presented a contract which patients had to sign on beginning TB therapy. Perhaps we need to consider a contract for donor agencies and partners in the South not to engage in TB therapy unless and until it will be done properly. In the words of

Professor Grosset from a meeting that we had several months ago while planning this conference, we should not initiate treatment unless we plan to cure. Incomplete treatment is clinically and ethically unacceptable.

Mirror Images of TB and HIV

This will not be the last question that we will face in this regard in the AIDS epidemic. Not long ago I received a communication from a colleague, a sister who is a physician serving in a developing country caring for persons with AIDS. She told me how well some of her patients were doing on anti-HIV therapy which she was occasionally able to acquire from numerous sources which unfortunately could not be counted upon to provide continuous drugs. She wrote to ask if I had any access to leftover drugs which could be used to help her patients feel better at least in the short term. I must admit that for several weeks I pondered how I would respond. I wanted to say that I had no access to leftover drugs, but in fact we have a big bucket of pills in our clinic from patients who could not tolerate drugs any longer. Occasionally they are very helpful when persons without access to insurance need a brief supply to supplement their ongoing anti-HIV regimen. But just as we face the question of how we are to deal with potentially incomplete capacity to treat TB, the Caritas AIDS Task Force has been struggling with the question of what to do with bringing antiretroviral therapy to developing countries. In fact, we know that drug companies are beginning to aggressively market these drugs - including protease inhibitors - in Africa. And while some individuals might be able to afford them as well as the viral load and CD4 cell monitoring which is necessary for them to be used properly, in fact in many situations patients are taking only one or two drugs rather than the minimum of three that is now recommended and this on an intermittent basis. While it may be quite true that these individuals will obtain a short-term benefit, just as in the case of TB, this is a recipe for disaster for the community in the long-term. This is because even relatively underdeveloped countries may be able to afford very short course monotherapy to reduce vertical transmission of HIV at the time of delivery, but any inappropriate use of antivirals in these populations would of course not only divert

scarce resources, but would also increase the level of drug resistance in the community, potentially obliterating the efficacy of affordable, short course monotherapy to prevent vertical transmission. I believe that these two issues should be seen as mirror images of each other.

Challenges to Bridge the Gap

A structural ethical issue at a larger level which came up several times yesterday has to do with the fact that, while treatment for TB is available and extremely inexpensive, in some circumstances countries in fact do not have these drugs available. This may be as a result of what we might judge to be misguided prioritisation of resource allocation - whether that means resources are going toward other health-care needs or toward military spending - or because of graft and corruption. When I joined the Caritas AIDS Task Force almost eight years ago, I learned about essential drug lists and naively thought that if a drug is considered essential, that must mean that someone is making it available. Of course, now I know that essential means that it is needed, but needed does not necessarily translate into provided.

The fact is that TB medications may not be available and this is contributing to the co-epidemic of HIV and TB. It would seem that we must squarely face the question of whether Non-Governmental Organisations (NGOs) want to step in to bridge this gap, to relatively inexpensively provide TB drugs simply because they are so cost-effective and the need is so great. Of course, this could also be an opportunity for governments to take advantage of the generosity of NGO's and we must ask whether this would set a precedent that in the long run is inappropriate, that, would send a message to governments that they can shirk their responsibility to provide these drugs.

Volunteerism

Finally, I want to briefly comment on our rather spirited discussion about whether or not volunteers from Zambia should in some way be compensated for the care they provide. This might not be in terms of money, but perhaps could be food or other items needed to support a family. It was evident that many of us in the North are accustomed to policies which preclude compensation to volunteers. However, as was so eloquently described yesterday, one must ask the question whether this understanding needs to be modified in circumstances of subsistence living. What does it mean to ask someone to volunteer their time if that means that their children will eat less as a result, or will not be able to have their school fees paid because of decreased employment? It occurs to me that one analogy we might consider from the scriptures is that of the widow's mite. Perhaps as we reflect on how volunteers are compared between North and South, we could say that "you in the North are accustomed to volunteering from your surplus, but those from the South have volunteered from the little that they had to live on." Should these not be considered as very different entities?

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THE ROYAL NETHERLANDS TUBERCULOSIS ASSOCIATION

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The Royal Netherlands Tuberculosis Association (KNCV) was established in 1903 as the national organisation for the fight against Tuberculosis (TB) in the Netherlands. Since then, KNCV has developed into a leading NGO in the field of TB control in the Netherlands and abroad.

Mission statement

To contribute to the global elimination of TB through the development and enhancement of effective and efficient TB control activities.

Objectives

- To support the development of sustainable TB control programs which detect as many infectious cases as possible.
- To apply country specific DOTS strategies in order to reduce mortality and morbidity from TB.
- To reduce the transmission of infection.
- To prevent the occurrence of drug resistance.

General Activities.

KNCV responds to the TB global emergency challenge:

In the Netherlands

- KNCV has been instrumental in maintaining an uniform and coherent delivery of TB control during drastic Health Sector Reforms in the late eighties. This resulted in further decentralisation of control services, including responsibilities for funding. TB control in the Netherlands resulted in one of the lowest incidences of the disease in the world. Based upon detailed epidemiological data, the elimination of TB as an endemic public health problem is predicted for the year 2030.

In developing countries

- In high prevalence countries the KNCV provides financial and technical support for application of the DOTS strategy, developed by Dr Karel Styblo in Tanzania, Malawi and Benin. Between 1984 and 1996 a cumulative total of 550.000 infectious cases has been treated in 8 supported countries. More than 85 % of these patients have been cured. There is an increasing demand for technical support from KNCV experts.

Core Activities

National

- *Guidelines and Protocol development*
KNCV is the Secretariat for The Netherlands TB Policy Committee which comprises representatives from various fields involved in TB control. The Committee develops guidelines for institutions dealing with high risk groups as well as professional standards for staff involved in TB control.
- *Surveillance*
The KNCV is responsible for TB surveillance in a joint programme with the Municipal Health Services and the Inspectorate of Health Care in The Netherlands. The KNCV surveillance provides valuable information for programme evaluation and for research in the country. KNCV also publishes the results of this surveillance in the annual "Index TB Of The Netherlands".
- *Technical support or policy development*
KNCV is the national authority which advises the Ministry of Health on TB control issues. KNCV co-ordinates national control activities and supports Municipal Health Services in implementing national guidelines.

International

- *Programme support*

KNCV is involved in programmes in Africa, Asia and Latin-America. Long- and short-term support is given in collaboration with several partners for local capacity building in all management aspects of a TB programme. Such activities include analysis of the current situation, project identification, technical assistance and project evaluation.

- *Policy development*

KNCV fosters policy debate and development through its membership of the Co-ordination Advisory and Review Group (CARG) and the Technical Research and Advisory Sub - Committee (TRAC) of the Global TB Programme of the WHO. Another important forum for policy development is provided through its membership of the International Union Against TB and Lung disease (IUATLD).

Supportive Activities

Training and capacity building

Training contributes to high quality control programmes. KNCV participates both nationally and internationally in the continuous education of public health physicians, clinical specialists, registered nurses and technical staff. It also contributes to international training courses for programme management on TB control e.g. in Tanzania and Vietnam. KNCV organises scientific national and international symposia. Since 1990, KNCV regularly hosted the "Wolfheze Workshops" for national TB programme managers. The aim of these workshops is to achieve consensus on issues pertaining to TB surveillance and control policies in European low prevalence countries.

Publications

Ample educational material for patients and the general public is available. A quarterly magazine "Tegen de Tuberculose" (Against TB) highlights developments in the fight against TB.

Research

The TB Surveillance Research Unit is a forum for TB research and is involved in operational research project in collaborating countries.

Through the International TB Surveillance Centre (ITSC), KNCV maintains an international standard for tuberculin surveys. KNCV houses both TSRU and ITSC. Various collaborative research projects are conducted, such as transmission surveillance through molecular epidemiology and drug resistance surveillance in the Netherlands, in conjunction with the National Institute of Public Health and the Environment (RIVM). KNCV aims at linking research with operational application of its results.

Documentation centre

Publications on many aspects of TB and TB control are collected and are accessible to professionals. The centre distributes up-to-date abstracts of the available literature and has a collection of audio-visual aids for training and education on TB.

International networking

The fight against TB can only be won through a concerted international effort. Sustaining collaboration is therefore an important aim for the KNCV and is accomplished through participation in world-wide conferences, both nationally and internationally.

Organisation

KNCV comprises 14 constitutional members, including the following organisations:

- The National Association for Municipal Public Health Services.
- The Association of TB Surveillance Officers.
- The National Association of Public Health Nurses in Municipal Health Services.
- The Dutch Thoracic Society.

KNCV is an organisation of health professionals, headed by a director who is responsible to the board. The director presents the annual and financial report at the general meeting. This meeting also approves of the work plan and financial budget.

Partners

KNCV collaborates with the following national and international partners in various countries:

- International Union Against TB and Lung disease (IUATLD): Malawi, Tanzania, Benin
- World Health Organisation (WHO): China, Indonesia, Ethiopia, Poland
- Netherlands Development Co-operation (DGIS): Kenya, Tanzania, Ethiopia, Zambia, Vietnam
- Royal Tropical Institute in Amsterdam, The Netherlands (KIT): Ethiopia
- Netherlands Leprosy Relief Association (NLR): Kenya, Sulawesi, The Gambia
- German Leprosy Relief Association (GLRA): Tanzania, Ethiopia
- Medical Committee Netherlands Vietnam (MCNV): Vietnam.

The International TB Platform (SIT)

In 1998 KNCV held a major international TB platform for Dutch development organisations and Non-Governmental Organisations (NGOs), to encourage greater collaboration between these organisations and their partners.

As a result 11 Dutch NGOs have decided to work together in the International Platform (called SIT) and therefore signed an official agreement. The platform has the objective to co-ordinate activities including enhancing

public awareness, raising political support, and creating sufficient resources.

Possibilities to collaborate with CARITAS/CIDSE organisations

KNCV provides support to those national TB control programs that are based on a well designed development plan. In some countries this support relates to regional programmes, which usually function as a pilot project for gradual expansion of DOTS on a larger scale. KNCV is very much interested to enhance co-operation with sister organisations like CIDSE/Caritas, provided that this collaboration is in line with its mission statements and objectives.

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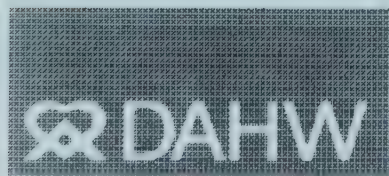
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INFORMATION ON THE GERMAN LEPROSY RELIEF ASSOCIATION

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Hilfswerk (DAHW)". Abroad it calls itself by the name of "German Leprosy Relief Association" (GLRA), respectively "Association Allemande pour l'Aide aux Lépreux".

General

The association bears the name of "**Deutsches Aussätzigen -**

The association was founded in 1957, the headquarter is in Wuerzburg. The German Leprosy Relief Association exclusively and directly pursues non-profit and charitable purposes, started to soften the misery and suffering of leprosy patients and became the leading NGO in the field of leprosy as a medical and social relief organization over the years.

Confronted with TB in the leprosy-endemic countries as a major health problem connected with poverty and stigma and aware of similar

possibilities of intervention like in leprosy, DAHW / GLRA started 1988 the support of TB work as combined leprosy-TB programs structured.

Promoting this combined approach is more cost-effective; the fact, that there are almost identical means for the control of the two diseases can make quality assurance easier and the pooling of knowledge and experience from leprosy and Tuberculosis (TB) is clearly beneficial to both programs.

Purpose

The German Leprosy Relief Association (DAHW / GLRA) is supporting the cure of and care for individual leprosy patients and TB patients in developing countries and the fight for a world without leprosy and less TB. The objectives of leprosy control are clear:

- provision of effective treatment for patients, using multi-drug treatment (MDT)
- reduction of prevalence and incidence of the disease
- prevention of physical and psycho-social disabilities
- physical and socio-economic rehabilitation of patients and their families.
- Fighting against TB is promoted by curing the patients' disease and restoring their capacities for activities of daily living and
- cutting the transmission and decrease the spread of TB-infection.

Activities

The core activity is the financial and technical support for leprosy / TB control projects which addresses the deficits of a program and goes mainly into training, manpower supervision, transport, laboratory services, health education and socio-economic services. In the year 1997, GLRA was able to support the cure and care of approximately 350.000 leprosy and TB patients worldwide.

In 1999 GLRA supports 306 projects in 44 countries of which 18 are integrated leprosy / TB programs.

Additionally, some special projects in leprosy as well as TB exist, namely:

- the Armauer-Hansen-Institut for laboratory quality assurance and drug resistance control
- the provision of technical consultancy
- the production of medical bulletins / guidelines
- the participation in International Training Centers
- the support of research.

For the financial and technical support of the programs and projects, GLRA has budgeted the amount of 27 million Marks (approximately 15 million US \$) for the year 1999.

Structures

A body of 39 members is electing the Board of Directors, which is governing a management committee, leading then the three departments of medico-social projects, administration and public relations / fundraising. Regarding the medico-social projects, the policy of GLRA is to support the implementation of current technology and available knowledge in leprosy / TB by putting it into effective practice in developing countries by using permanent technical and administrative advisors within the country - to transform advice into reality.

Fundraising and Public Relations

Besides very limited financial contributions from the German Government and the European Union, more than 95 % of the GLRA income comes from individual donations. This needs continuing lobbying for the problems of leprosy and TB patients by creating public awareness in the electronic and print media and it deserves a permanent dialogue with hundred thousands of donors in Germany. The donations in the year 1998 amounted to 32 million German Marks (approximately 17 million US \$).

Co-operation

GLRA was very much involved in creating the International Federation of Anti-Leprosy Associations, known as ILEP. While retaining their autonomy and making their own decisions, the 20 ILEP Member-Associations coordinated their grant-giving through the mechanism of the Federation: an Information

Network with standardized forms, centralized files and directories and analyses of the information obtained; an annual Working Session and a system of country and project coordinators. These mechanisms help avoid overlap and provide concentration where it is most needed.

Technical cooperation is provided by a Medico-Social Commission and TALMILEP - a joint project to produce and distribute teaching and learning materials in leprosy and nowadays also in TB. In TB an international

coordination was started in 1992 with participation of WHO, IUATLD, KNCV, DAHW/ GLRA and LHL.

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CHURCH – SPECIFIC RESPONSE TO HIV/TB

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Church and TB/HIV

The Church's mission is none other than that of Jesus, to "preach the good news to the poor, proclaiming freedom for prisoners and recovery of sight for the blind, releasing the oppressed and proclaiming the year of the Lord's favour". HIV/AIDS (and related conditions like Tuberculosis (TB)) brings suffering, pain, alienation, despair and death. It is not just a medical problem, it is also a social, psychological and spiritual/moral problem. The vicious circle of HIV/AIDS and poverty in developing countries has made AIDS also a very serious development problem which affects the communities as a whole. People with HIV/AIDS are asking fundamental questions related to God and heaven, life and death, forgiveness and condemnation, salvation and eternity: questions that are calling upon pastoral and spiritual counselling which cannot be provided by the medical professionals. People with HIV/AIDS/TB are subjected also to stigmatisation, rejection, oppression of their human rights. If the Church is the bearer of Good News, she must of necessity be concerned in the face of such misery and despair. The Church through her members and especially her ministries is the nearest and often the only available and accessible refuge in crisis situations.

The Church must be seen as a serving, healing, CARING community, ministering to all people in her three fold capacity of priest, prophet and king. As "priest", she must counsel, console, encourage, forgive and reconcile; as "prophet" she must teach God's truth, announce, warn, correct, encourage and rebuke when called for without fear or favour. She must act as the conscience of society and government, questioning and protesting in the strongest terms any discriminatory policies and practices; as "king" she must ever strive to bring people together and lead them into green pastures. The Church must come down from the pulpit and meet the needy in the streets, in the shanty areas, in hospitals, prisons, etc and walk with them as Jesus did. Jesus did not shun lepers or prostitutes but walked with them, ate with them, healed them and brought hope to their lives. The Church must do the same. She must set aside all temptations to be judgmental and denounce any suggestion from whatever source that HIV/AIDS is a punishment from God. The Church at every level must get involved in the struggle to prevent HIV/AIDS and to care for those already infected/affected. She must answer the questions of those who are in fear and despair, she must mobilise all available resources in this fight for a better future for the people of God.

Response of Ndola Diocese, Zambia

Among the Sub-Saharan countries, Zambia is one of the most seriously affected ones by the HIV/AIDS pandemic and the consequent increase of TB cases. It is also the country which is most affected by the increasing number of orphans. The Catholic Church has been always involved in the provision of health care but, in the past Church health institutions were mainly located in rural areas where government services were mostly lacking. Since the advent of the HIV/AIDS epidemic the Ndola Catholic Diocese has been in the forefront to organise and support community based initiatives in the peri-urban areas (shanty compounds). This has resulted in the implementation of the AIDS Department coordinating and supporting 11 Home Care Programmes in 5 towns of the Copperbelt Province. These programmes are interdenominational in the sense that community volunteers are selected by the communities from different Churches. Unfortunately, the action taken at the top level from other denominations to fight HIV/AIDS and organise care for the infected/affected is quite dormant.

The vision statement of the Catholic Diocese of Ndola is based on the following beliefs: The Kingdom of God is truly within people. People themselves are the owners of their development and are able to bring out their own potential for growth. Holistic development of people and communities can be achieved through participation and sharing without discrimination of any kind such as race, tribe, gender, religion, age or status. In this way, obstacles which are rooted in political structures, traditional and cultural beliefs, economic injustice and religious beliefs can be better removed. People can grow and develop best not in isolation but mutually as a community.

According to this vision, the Health Department of the Catholic Diocese of Ndola has always worked closely with the Development Office and other Diocesan Departments. A "training for Transformation" is offered on request to the communities which are involved in home care programmes and to the Small Christian Communities.

Ways to a Holistic Approach of Care

We have seen that the Church has a great contributing role to play towards the building up of community based health development services since it enhances ownership and participation from the communities and provides high motivations among health workers and community volunteers. The Church can also contribute significantly with its ethics and values to promote a holistic approach to care. The need for a holistic, continuous, integrated, effective care as emphasised by the HIV/AIDS epidemic is, in fact, a similar right for other chronic and terminal ill patients as well for all patients. Home Care Programmes, initiated by the communities through the leading role of Churches will have the spin-off effect of changing the attitude of the medical professionals. Another effect will be to shift the idea of Public Health owned exclusively by the Government Health Services to the vision of a Public Health owned by the communities, focussed on multi-sectorial approach, rooted on human rights and requiring the Government to take and guarantee a supportive role.

In Ndola Diocese the Church has been very active in the provision of hospital care, home care programmes, counselling services, income generating programmes, orphan support programmes, preventive activities etc. This kind of support programmes has been developing during the years, especially through the involvement and mobilisation of lay people from the Small Christian Communities and Religious Congregations.

Roles and Responsibilities of the Clergy

Still the local clergy are very little involved in the pastoral and spiritual care of those affected by AIDS and in the denouncement of the root causes behind the vicious circle of poverty and AIDS. Sensitisation and awareness workshops for Priests and Pastors on HIV/AIDS and related issues are very much needed. The Church is also a worshipping community that gathers all its members together without exclusion or differentiation, without judgement of sexual behaviour or orientation. Its liturgies, prayers and symbols need to speak of acceptance, to bring meaning into a reality where large numbers of young people are

dying of AIDS and many others affected by the virus are searching for hope, to denounce injustices provoked by HIV/AIDS. Its ministries, the Priests, the Pastors have a great responsibility in showing to the others the Fatherhood of God and the love and care He has for His people.

The Tree Model Leading to the Roots

When we look at the HIV/AIDS epidemic and its impact especially in the developing countries we can analyse it by using a causal model, e.g. the problem tree. In this model, the tree trunk represents the problem of rising levels of HIV/AIDS. The branches and leaves are the effects of this problem. To understand the causes of the problem we have to go deep and look at the roots. The immediate and most obvious roots will in turn have their deeper contributing roots that need to be unearthed and identified. These are the factors that determine the shape and size of the trunk/problem. Any response of the Church that is solely concerned with deductive / proscriptive teaching, with compassionate and benevolent care or with clichés and involved worship, can, at best, only hope to alleviate the damage of the branches and leaves or, at worst, to steel the lymph needed to give life to the tree.

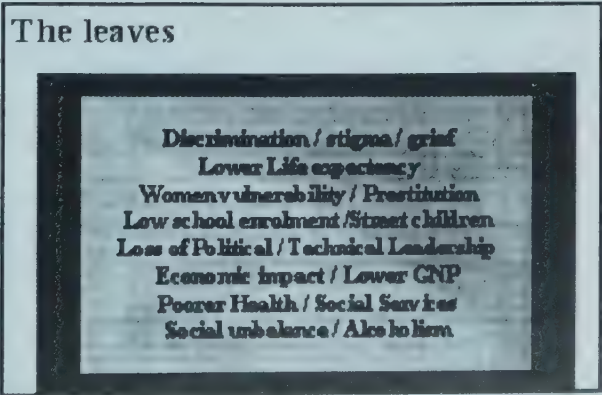
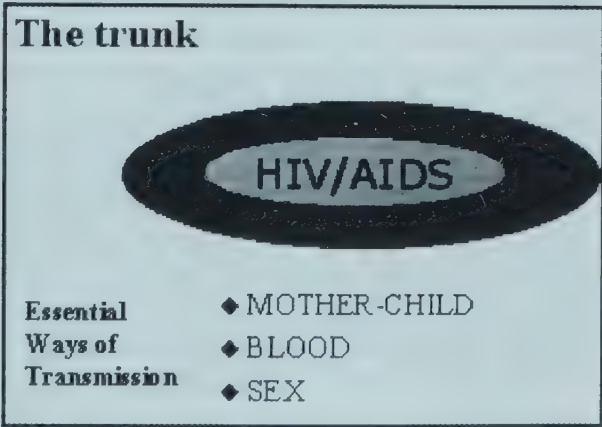
To be effective the response of the Church needs to go below ground and tackle the complex and multiple factors contributing to the problem. Change will only come when we are prepared to work at the roots. As the model shows the main root is the poverty due to the disparity between North and South in the world. This has its underlining causes in several others roots (international debt, IFM/WB policies, SAPs, multinational companies, military arms trading, consumer's attitude etc).

The Church is already taking a leading role in asking for the debt relief and denouncing the existing world disparity. This task of being voice of the voiceless should be intensified and shared by all Christians and people of good will. If the debt relief will come for the year 2000, it will be an essential starting point for many developing countries but mechanisms of monitoring the use of the money saved, should be put in place. The Church can have a great

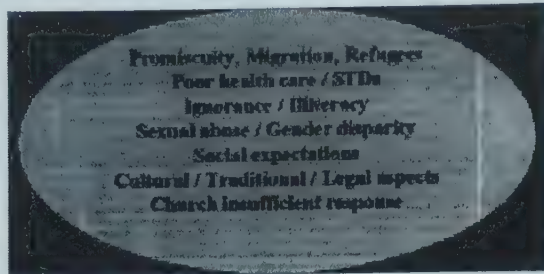
role in acting as a watch-dog on governments and politicians so that this money will be spent to alleviate poverty and invested in health, education, agriculture etc. To tackle these deep roots is a challenge for all of us formulating, in our own context, the Church's specific response to HIV/AIDS.

In the Catholic Diocese of Ndola there will be the need of working and focussing intensely on awareness process within the communities, capacity building, leadership, training for transformation, development and empowerment of vulnerable groups (e.g. women). All these plans require funds that the Diocese, at the moment, doesn't have. A Church's work will be also to find and utilise resources for it. We appeal to Caritas International, CDSE and other Church related organisations to come out stronger in the international debate for alleviation of poverty and distributive justice. We appeal also for their support to development programmes and community based initiatives for care of those infected/affected by the HIV/AIDS pandemic in the poorest countries in the world.

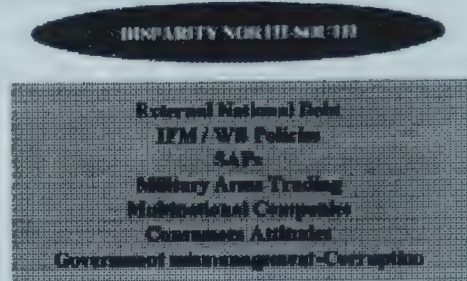
The Root Model



The nearest roots



The deepest roots



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INTEGRATION OF TUBERCULOSIS INTO COUNSELLING SERVICES IN RUBAGA HOSPITAL

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Feasibility of DOTS

Direct Observation of Treatment, short course (DOTS), a strategy launched by the World Health Organisation (WHO), has been proven to be efficient to control Tuberculosis (TB) in different settings and places. However despite being cost - effective, it may not be affordable to both, the health facilities especially those in developing countries and the patients. Due to organisational constraints and special local circumstances, it may overstretch the possibilities of health care facilities and may turn out not to be feasible in the daily practice.

Background

Since 1990, a National TB and Leprosy Control Programme has been implemented in Uganda. It's operations are based on WHO recommendations. One element of the programme is free drug supply. The National TB Programme is not working well in the capital city of Kampala due to factors linked to

the urban setting. At Rubaga Hospital, one of the four major hospitals in Kampala, it was not possible to treat 700 TB patients a year under direct observation of treatment due to lack of space, manpower and the limited financial resources of both, the patients and the hospital.

Consequently, the patients were registered and instructed only once about the disease at the beginning of their treatment. They were then followed up fortnightly in the first two months of the intensive treatment period and afterwards monthly during the continuation phase. As in many other settings elsewhere, this procedure caused a high rate of defaulters and too few patients were cured.

Rational of the Research Project

Searching for an appropriate alternative strategy, the hospital management team developed the ideas, to involve the patients and the community more actively in the control of

TB by continuous teaching and counselling during the treatment period. The HIV counsellors of the hospital were trained additionally in aspects of TB disease, prevention and care. Teaching materials have been developed; the patients were counselled fortnightly when they came to fetch drugs for their treatment.

The output of the modified counselling services was evaluated in a randomised, prospective, controlled trial having one group continuously counselled and a control group only instructed at the beginning of the treatment period. The study was performed between March 1997 and February 1998. All patients were interviewed with the help of a standardised pretested questionnaire in order to assess their knowledge about Tuberculosis, their affective reaction (seriousness, severity and stigma of TB) and their attitudes at the beginning and after 10 weeks of treatment. An entry was made on the registration card indicating if patients fetched their drugs timeously.

Results

The hospital administration had been very sceptical towards the study. But the new counselling service turned out to fit very well into the hospital's daily life. Apart from two new counsellors, no additional staff was necessary. Despite the financial problems of the hospital, the management board decided to implement the counselling service as part of the management of TB patients after the study was completed.

The patients accepted the counselling very well. There was a great demand from the patients for further information and counselling. Out of 340 patients, only 11 patients (3,2%) refused to talk about TB and related problems. As TB is highly stigmatised and often linked with HIV, the counselling was found very helpful in discovering misbeliefs, correcting wrong ideas and talking about fears and how to overcome desperate situations.

The questionnaires confirmed, that there were a lot of insecurities and misbeliefs, especially regarding appropriate behaviour leading to cure of oneself and prevention of infecting others. The counselling service effectively improved the patients knowledge about TB. While only 6 out of 16 scores could be achieved in average asking 8 questions about TB more than 2/3 of the total score was reached in average after education. In the control group there was no change. The total defaulter rate during the first two months of treatment was too low to confirm any possible statement. Only 36 out of 261 patients (14%) defaulted. However, it seems that the defaulter rate is markedly higher in the control group (65 %) than in the counselled group (35%).

Conclusions

Global strategies to fight the TB epidemic may have their limitations as a result of local factors which influence their realisation. Involving the patient actively in the control of TB seems to be a promising aspect, as the example of the Rubaga Hospital shows. Integration of Anti-TB activities into existing health care structures on the primary level can be a sustainable and efficient alternative to programmes organised vertically. Additional efforts on the decentralised level can be fruitful when they are adapted to the specific setting and use the resources that are already in place (infrastructure, manpower and financial resources). Regular counselling of the TB patients seems to have a major impact on adherence to treatment. It can be performed easily and requires only minor additional resources. Almost no additional resources are needed if HIV counselling services already exist.

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MISEREOR'S APPROACH TO TUBERCULOSIS

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The importance of the problem

Tuberculosis (TB) is probably the world's worst disease. It is affecting the poor and the disadvantaged in particular. Therefore efforts to alleviate the lot of the poor are likely to impact on the TB problem. This fact notwithstanding, specific health interventions are also required. At present TB kills more people than AIDS and malaria together. One third of all AIDS deaths are caused by TB (WHO). Everybody who is concerned about AIDS, therefore needs to have a genuine interest in TB.

Misereor's involvement

Misereor's approach in the past has been that of its partners. It also reflects contemporary fashions in international health. In the 1960s TB was in the limelight and Misereor was involved in supporting large scales TB programs, primarily in East Africa, but also in Algeria and in India. Interest in TB control waned in the 1970s and 1980s and Misereor's support shifted to occasional assistance of local and regional initiative. In the late 80's at the beginning of the AIDS crisis Misereor supported an intermediate drug supply to the TB programme in Uganda accompanied by technical expertise. Analytical work done in the course of this project showed substantial deficits of church-related hospitals in their approach to treating TB, indication that material support alone – that is without technical support – would probably not help to improve the situation. The need for appropriate information about TB was addressed in the collaboration between the IUATLD and Misereor in the edition of the TB Guide, now in its 4th edition, which has become a widely used source of knowledge about TB in developing countries. The most important partner of Misereor in TB since the 1960s has been the International Union against TB and Lung Disease (IUATLD).

Importance of DOTS

In respect to health interventions against TB: "Directly observed therapy (DOTS) will decrease duration of infectiousness, virtually guarantee cure and prevent drug resistance." Despite of substantial progress in making DOTS more widely available, the WHO has recently reported that at present only 15 % of all persons with TB have access to DOS. Even though TB control is primarily the responsibility of government, mobilising the potential of church related health care providers would probably be helpful to increase the uptake of DOTS in low income countries. In particular this holds for sub-Saharan Africa, where a large share of all health care is provided by churches. However, as failure to cure TB does not only harm the patient but also the community by making the TB untreatable as a clinical and a public health problem a number of questions come to mind in thinking about possible strategies for that.

The quality gap

At the health services level best practice needs to be ensured, diagnosis by microscopy, use of standard drug regimens in treating the disease, documentation of the treatment outcome, a regular drug supply and trained staff are key elements. Even though this has not been systematically studied, available information of present practices in TB care in church related health services point at substantial and potentially harmful quality gaps. It is neither the question at what level TB should be treated, i.e. hospital, health centre, dispensaries level nor if community health workers or home care takers should be involved than the question of best practise of treatment. At the health system level church related services getting involved in TB treatment need to establish a strong co-operation with governmental initiatives and programs of TB control.

Need for a contract approach

This is not always possible. New ways for expanded public private partnerships are urgently needed i.e. like actual initiatives based on the contractual approach. Donors supporting church related health care providers wishing to get involved in TB control have the responsibility not to do harm in the first place (*primum nil nocere*). This implies, that support for TB programmes should only be given when the necessary managerial and technical capacity is either present, or can be created by combining material with technical support. TB cannot be cured with funds and enthusiasm alone, it needs a sound technical approach! Therefore church related donor agencies wishing to increase their support for TB care probably will need the co-operation of organisations that have the necessary expertise to provide adequate technical support (i.e. the International Union and national TB societies, ILEP organisations and independent TB consultants).

New interventions: DOTS has been shown to be both effective and cost effective under most circumstances. This is not quite the case yet for the recently recommended preventive chemotherapy for persons living with HIV. Therefore, it does not appear to be feasible to build a strategy for expanding TB care in church related health services on the new approach. For the time being preventive chemotherapy appears to be too much

complicated for routine use in most health care settings in sub-Saharan Africa. It has to be kept in mind that health services where HIV and tuberculin testing, chest X ray, sputum smear examination and adequate counselling services are continuously available are still quite rare. Moreover it has been recommended to use preventive chemotherapy only in situations where a DOTS program exists and persons diagnosed with TB can be treated adequately. All this does not preclude to preventive chemotherapy in a limited number of projects in order to learn more about its practical feasibility. The availability of a feasible health intervention preventing TB in persons living with HIV would be clearly desirable.

Conclusion

In practical terms the primary challenge concerning TB care in church related health services is to ensure cure in those who have TB. Only after that, PT may be an option.

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LESSONS LEARNT FROM THE IMPLEMENTATION OF COMBINED LEPROSY / TB CONTROL PROGRAMMES

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German Leprosy and TB Relief Association

Introduction

The discovery of TB drugs is a triumph of science. However, the failure to control TB is a disgrace to mankind. We are able to fly to the moon, but not able to control TB and prevent death from many TB patients despite excellent drugs and excellent strategies! Therefore the

improvement of TB control is a real challenge and obligation and we have to learn from past experiences. In the following lessons learnt from the implementation of combined leprosy and TB control programmes will be presented.

Combination is feasible and successful

The combination of leprosy and TB in one control programme is well possible, as there exist many similarities between leprosy and TB. The same method of control, namely case finding and treatment, the same method of diagnosis, the microscopic examination of smears stained by Ziehl-Neelsen, the same problem of compliance, as both diseases are chronic, partly the same drugs, e.g. Rifampicine, etc. The combination of programmes is useful. The cost-effectiveness increases, especially concerning the cost per patient. Leprosy is a decreasing problem, therefore it becomes less a priority and through the combination with the 'big brother' TB, leprosy remains on the agenda. The TB side gains by having access to additional resources. The combination has been applied with success in over 30 countries.

Key elements of control

The control of TB and leprosy (TBL) is in theory simple. Only four major activities are required. Find the suspects of leprosy and TB, diagnose them - the WHO target is to find 70% of the estimated case load -, treat them well - the WHO target is to cure 85% - and the last activity is to record some data for monitoring and evaluation purposes.

Constraints and pitfalls

However TBL control is in practice difficult. All of the four above mentioned activities have their own problems and constraints, which we can divide in two categories. The material and financial problems and the manpower problems. The material and financial problems are relatively easy to overcome and to organise. The manpower problems are much more difficult to manage. The task of the manpower is to work with above material and financial resources in the right way and to treat the patients well. However, lack of technical and financial support de-motivates the staff resulting in poor quality of TBL control. The staff is often not doing what needs to be done.

Let's look now to the four major activities of TBL control in more detail. The first activity: to find the suspects. This is done in a passive way. If the awareness of symptoms is present among the population, if the accessibility to a

laboratory is guaranteed - a network of microscopic centres, 1/100.000 pop. would be ideal. If the quality of service is guaranteed - if other patients are well received and cured by the service -, then patients will come forward on their own. The second activity: to diagnose the patients. This subject including the quality assurance of laboratories has been treated in a lecture by Dr. Bretzel (GLRA). The third activity, to treat the patients well. Leprosy and TB are chronic diseases and have to be treated between 6 to 12 (leprosy) months. Therefore there is a compliance problem. Especially the TB patients feel already much better after a few weeks of treatment. If they have not received health education, they may not see the need to continue the treatment and may disappear. The answer of WHO to this compliance problem is daily DOTS, this means to take the treatment under daily direct observation, either in a hospital or on an ambulatory basis. The responsibility lies with the health worker, or in case of community DOTS with a community member, in any case, always with somebody else, not with the patient. The advantage of the DOTS strategy is, that it has given in many programmes much improved results. However, there are also several disadvantages. The strategy is too dogmatic. Daily observation is in many situations difficult to realise. It is also too expensive for patients to go daily to the clinic. In many areas, where there are no clinics or health workers, the strategy is not possible. And most importantly, the strategy excludes the patient from the responsibility for cure. He is not allowed to take the pills himself, but somebody else has to observe him.

'An alternative to DOTS'

The answer of GLRA is to introduce a strategy of flexible DOTS. The patient is from all participants around the compliance problem in principle the most motivated one. He is ill, he wants to be cured. Only he needs to be well informed. If he is informed and convinced, that compliance for 6 - 8 months is necessary, he will take the drugs regularly. Therefore the patients are to be included in the DOTS strategy. DOTS should be a shared responsibility between health worker and patient. E.g. a weekly DOTS scheme could be introduced, which means that the patient comes only once a week to a clinic, where the

drugs are taken under observation of a health worker and the other 6 days the patient takes the treatment at home. The advantages of the weekly DOTS are: the strategy includes the patient. It is a more flexible approach, therefore everywhere possible, e.g. in Ethiopia, where in large areas no health facilities are present. It is much less expensive for the patient, instead of paying the taxi 30 times, he pays now only 4 times per month. The health facilities are less overburdened than with daily DOTS. In studies in Nigeria and Indonesia it was found, that weekly DOTS gave the same or even better results than daily DOTS.

Blister pack – an important tool

If the patients take the drugs for a week at home, it is important that the drugs are available in a good presentation. Therefore a weekly blister of TB drugs was developed. It contains Ethambutol, Rifampicine, Isoniazide, Pyrazinamide and only 4 tablets per day, instead of the customary 9, have to be taken. A blister is easy to use and hygienic, less errors are likely to be made than with the loose drugs and there is a possibility to check the drug intake by requesting the patient to bring the empty blister, at the next clinic visit. The calculation of the drug need, distribution and stock management becomes also easier.

The decentralisation of TBL services

It is important that the TBL services are decentralised for increased accessibility. As was pointed out earlier, a network of microscopic centres should exist of 1/100.000 pop., concerning the treatment points, a network of 1/10-20.000 pop. would be ideal. And with above mentioned home treatment, decentralisation is then up to the homes of the patients. It is worthwhile to mention that decentralisation is good for the accessibility, but the assurance of the quality through supervision becomes more and more complicated and difficult.

Conditions for Integration

Integration of disease control, like for leprosy and TB, into the basic health services is only possible, when such services exist and function. If not, then the TBL control programme has unfortunately to remain

vertical. But in most countries TBL control programmes are not vertical. The basic steps of TBL control, which is case finding, treatment and recording, are executed by general health workers in general health facilities and are thus integrated. Only the quality assurance aspects - central management, supervision and training - are executed by specialised leprosy and TB staff and are thus not integrated. This should remain so, as at this level a specialisation is required, but despite non-integration the quality assurance aspects can be combined and TBL training and supervision are a good example of such a combination.

The health information system

The last major activity is to record some data in order to be able to monitor and evaluate the programme. The data are recorded on a patient card and a district register. Essentially only two indicators have to be known.

1. How many patients have been found.
 2. How many of above reported patients (which is a cohort) have been cured.
- Unfortunately data are not always reliable and regular checks are necessary.

Quality assurance

This aspect of TBL control is of crucial importance. The implementation of the four major activities: finding the suspects, diagnose them, treat them well and record some data is only of value, if the activities are well done. The NTLP services must be of good quality, otherwise they do more harm than good. If the quality is lacking, many patients will not be cured and multi-drug resistance (MDR) will appear and make TB control impossible. As said before, the problem of quality assurance is not in the first place linked to material and financial resources. Clearly they have to be there, otherwise the programme cannot start. But the main problem is with the manpower and the question how do I motivate a person to execute the given tasks as well as possible. A major tool to solve this problem, is to give the health workers regular technical and financial support, in the form of training, supervision and incentives.

Motivation of staff

Training, which is well done transfers competence and motivation. Therefore training should be task oriented, only essentials should be taught, standardised curricula could be a help and very importantly, training should always be followed up by visits to the working place of the trainees, because implementation of learnt issues is difficult and regular on the spot training is therefore necessary. Of all the tools to motivate the manpower to improve the services, regular supervision is one of the most important ones. The peripheral health workers should not be left alone. Everybody needs a sign of interest and encouragement. Therefore regular supervision of good quality with a standard protocol, checklist and on the spot training is necessary. It is important to make a yearly schedule of supervision in advance and to make of each visit a report plus recommendations, which should be followed up. Supervision should always be a supportive and encouraging activity, not only a control exercise. If the salaries of the staff are

subsistence, which is often the case, then a financial assistance in form of incentives or allowances may help to increase the motivation. However, money alone will not solve the issue. Support to the staff in form of regular training and supervision is more important.

Conclusion

Finally TBL control is well possible. The tools and strategies are available. We need only to implement them in the right way.

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QUALITY ASSURANCE FOR SPUTUM SMEAR MICROSCOPY IN TB CONTROL PROGRAMMES SUPPORTED BY THE GERMAN LEPROSY RELIEF ASSOCIATION

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Introduction

Each undiagnosed and untreated case of smear positive TB (TB) infects on the average twenty persons before either dying or becoming smear negative. Of these twenty infected persons on the average two develop the disease, one of them being smear positive, thus sustaining a steady chain of transmission (1, 2). Furthermore, undiagnosed and untreated TB is associated with a high mortality. The fact that the majority of TB deaths in the developing world occur in the economically most

productive segment of the population from age fifteen through fifty-five causes high costs for society and economy (3)

Therefore, the most important objective in the TB control is to find and cure as many of these infectious cases as possible to prevent further transmission of the disease. The major diagnostic tool for the detection of infectious, smear positive TB cases in developing countries is sputum smear microscopy. Although sputum smear microscopy requires at

least 10.000 acid fast bacilli per millilitre to be effective, many studies have proven that sputum smear microscopy – if carried out properly – performs well under field conditions for the detection of highly infectious smear positive cases (4).

Proficiency tests carried out in various developing and developed countries however, suggested a poor performance of many laboratories reporting less than 75 % to 80 % of correct results (5). With regard to the key role of sputum smear microscopy, the proficiency of microscopy units needs to be monitored continuously. Under the guidance of its supranational reference laboratory, the Armauer Hansen Institute of the German Leprosy Relief Association (GLRA) has developed a programme for quality assurance for microscopy services in GLRA supported TB control programmes. It consists of several elements: quality control of sputum smear microscopy, standardised laboratory supervision and standardised training for laboratory technicians.

Quality Control

Quality control comprises internal quality control measures and external proficiency testing (6, 7). Internal quality control measures lie in the responsibility of the laboratory. It refers to the following elements:

- personnel: employment of staff with appropriate training in sputum smear microscopy
- workload: the average daily workload per technician must not be too high, insufficient submission of specimens however may compromise the test's diagnostic reliability
- laboratory procedure manual: sputum collection, identification of specimens, smearing and staining, recording and reporting, safety precautions
- checking of reagents: the regular (optimum: daily, minimum: each new batch of stain) use of positive and negative control smears for both fuchsin-based and fluorochrome AFB stains
- recording and reporting: minimum information on request forms, laboratory register and reporting forms: name of requester, requested test, patient's name or other identification, basic demographic

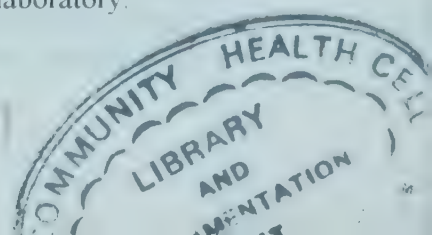
data (age, sex, address), date of collection, date the laboratory received the specimen, procedures performed, personnel performing the test, exact documentation of results

- facility requirements: availability of adequate space, lighting, ventilation, water supply, safety precautions
- equipment: regular cleaning, function check, and proper storage of microscopes and other items

External proficiency testing (external quality assessment) refers to a system of objectively assessing a laboratory's performance by means of an external agency. This assessment is thus retrospective, and by this means different laboratories can be compared. It is recommended that all laboratories participate in an external proficiency testing programme that is approved by the National TB Control Programme/ Ministry of Health of the respective country (8, 9).

According to the IUATLD, quality control of sputum smear microscopy is defined as a method of ensuring the quality of diagnosis and classification of TB patients within the health-service, based on the re-examination of a representative sample of all patients cared for within the health service and should include a re-examination of both positive sputum smear results and negative smear results (10). Several approaches to quality control/proficiency testing have been used in mycobacteriology (9):

- central to peripheral approach: the reference laboratory sends sets of stained and/ or unstained test slides to the peripheral laboratories in order to evaluate the proficiency in smear microscopy.
- peripheral to central approach: the peripheral laboratory sends selected slides to the reference laboratory.
- modification: laboratory register based approach (the supervisor selects the slides from the laboratory register and forwards the slides to the reference laboratory).
- TB district register based approach: the supervisor selects slides from the TB district register, collects the slides from the respective laboratories and forwards the slides to the reference laboratory.



- **on-the-spot (on supervision) approach:** the supervisor performs "on the spot" quality control during his/her regular supervisory visits in peripheral microscopy units by randomly picking and examining slides in each laboratory.

It is important to note that regardless of the method being applied, external proficiency testing programs will only be successful if coupled with education and training of laboratory staff. It is essential to provide feedback to the participating peripheral laboratories by means of regular on-site visits and laboratory supervision and subsequent training programmes.

Pilot projects on quality control of sputum smear microscopy in Uganda

In order to assess the feasibility of different approaches to quality control for sputum smear microscopy and to obtain baseline data on the prevalence of staining and reading errors, several pilot projects have been carried out in Uganda. The preliminary results of a study in Rakai district are presented below.

Study design

Sampling method: district register based method

Sampling period: 4th quarter 1997 until 3rd quarter 1998

Sample size: 242 slides from 7 peripheral microscopy units

Supranational reference laboratory: Armauer Hansen Institute, Germany

Results

Accordance of results (peripheral laboratories – reference laboratory):

78.1 % identical results

4.1 % minor differences in grading

16.9 % false positive results

0.9 % false negative results

Quality of material and staining:

9.9 % saliva

79.3 % precipitates/crystals

40.5 % too thick or too thin

22.3 % other bacteria/yeast

In view of these findings the following remedial action has been taken. In order to provide feedback to the peripheral laboratories the supranational reference laboratory has been

sending individual letters to the participating laboratories commenting on the findings. The GLRA medical consultant and the district supervisors subsequently discuss the findings with the peripheral laboratory technicians on laboratory supervision.

In addition, the staff of the supranational reference laboratory carries out laboratory supervision and on-the-job training in selected laboratories at least once a year. In our opinion it is essential for the supranational reference laboratory to establish such a direct contact with the peripheral TB laboratories and to visit the peripheral laboratories on a regular basis in addition to the compilation and analysis of data on the prevalence of staining and reading errors.

In the meantime quality control for sputum smear microscopy (using a laboratory register based sampling approach) has been implemented in 10 of the 19 GLRA funded districts of Uganda. Quality control is carried out at two levels. Presently two national/regional reference laboratories examine the slides from the peripheral laboratories and a representative number of those slides is re-examined at the supranational reference laboratory in Germany.

Standardised laboratory supervision

The laboratory network of the National TB and Leprosy Control Program (NTLP) Uganda presently consists of a total of 284 microscopy units attached to hospitals and peripheral health centres. 123 diagnostic units are located in the three GLRA supported zones, 14 in Kampala, and 147 in the remaining five operational NTLP zones. There is on average one microscopy unit per 60.000 – 75.000 inhabitants (1 unit per 73.000 in the GLRA supported area).

Laboratory supervision is carried out by the District TB and Leprosy Supervisor (DTLS) on his/her quarterly visits to the health units in his/her district. The DTLS' responsibilities include ensuring laboratory supply, checking on laboratory request forms and laboratory registers and to make sure that treatment and follow up sputum specimens are examined at the required intervals. Furthermore, the DTLS is supposed to collect slides for quality control

and to identify candidates for refresher courses in smear microscopy.

In general however, the DTLSSs are not trained in laboratory matters and do not have a background in microbiology. Therefore, apart from a few exceptions, the "average" DTLSS does not really know what exactly to check on and ask for in the laboratories. On questioning, some DTLSSs admitted they were even "afraid" to approach the laboratory as they do not know how to perform supervision there. According to their background, knowledge and training, the DTLSSs are capable of ensuring supply of laboratory reagents and checking on laboratory registers, but it is very difficult for them to fulfil other tasks, e. g. to supervise the collection of specimens, to collect slides for quality control and to identify training needs. By no means, the DTLSS is capable to assess the performance level of laboratories and to identify or correct technical problems. In view of that situation, one may conclude that DTLSS supervisory activities resemble rather social visits than real laboratory supervision.

In addition, a supervisor from the Central Reference Laboratory is supposed to visit each laboratory in each district at least once a year. His task is to assess the performance of the laboratory technicians, to ensure that smearing, staining and reading of slides are performed correctly and to find solutions for technical problems. He also carries out on-the-spot quality control. In order to assess the general laboratory situation and the efficiency of the present laboratory supervision system, staff from the supranational reference laboratory/GLRA headquarters and GLRA Uganda have carried out annual supervisory visits in selected districts since 1997. These supervisory visits focused on shortcomings in supply of laboratory reagents and materials, laboratory safety, sputum collection and the level of training and knowledge of the laboratory workers. These findings clearly proved the need to reorganise and to improve laboratory supervision in Uganda.

Checklist for standardised laboratory supervision

In order to provide a tool to facilitate laboratory supervision for the supervisors in terms of fulfilling their above mentioned

duties, a checklist has been developed. The checklist contains two sections, one for the non-microbiology trained DTLSS, and one technical section for the supervisor from the Central TB Laboratory.

- Section for the District Supervisor:
 - General Requirements (space, water, light)
 - Laboratory Reagents
 - Laboratory Equipment
 - Safety Measures and Waste Disposal
 - Collection of Sputum Samples
 - Laboratory Request Forms and Laboratory Registers
 - Quality Control
 - Training Requirements
 - Workload
- Section for the supervisor from the Central Laboratory
 - Bacteriology/Technical Aspects

The checklist provides a tool for the supervisors which helps them to carry out efficient laboratory supervision, to collect the relevant information and to forward this information in a standardised manner to the Central Unit. Based on this information, the Central Unit can then take remedial action if required.

First experiences with the checklist

The checklist has been introduced in 11 districts of the country since 1997. A comparison of 16 laboratories before and one year after the introduction of the checklist revealed clear improvements regarding the following:

- availability of reagents
- sputum collection, staining and microscopy
- patients are properly instructed how to produce sputum
- staining solutions are filtered
- 100 fields per smear are examined
- laboratory safety
- disinfectant and biohazard waste bins are available
- laboratory staff know how to avoid dangerous airflow
- sputum cups are decontaminated
- lab technicians wear lab coats.

Identification of training requirements

The preliminary findings presented above suggest to consider the checklist as an important and useful tool for monitoring the performance of peripheral laboratories and enhancing their crucial role in TB control. The checklist provides assistance in laboratory supervision for supervisors without a strong background in laboratory matters. It turned out to be helpful in identifying shortcomings of any kind and providing appropriate and timely supply with laboratory reagents and other items required to carry out sputum smear microscopy. It helps identifying training needs and contributes to educating both, supervisors and laboratory technicians in matters of laboratory safety and basic bacteriology.

Based on the first encouraging experiences with the checklist in 11 districts of the country, it will be implemented in the remaining 8 districts of the GLRA supported NTLP zones. The data will be entered in a database and analysed quarterly in order to monitor the performance of laboratory supervisors as well as the performance of the peripheral laboratory network in Uganda.

Training and Education

Training of laboratory technicians is one of the essential tasks of the national TB reference laboratory. The national TB reference laboratory also has the responsibility to write a training curriculum and a manual of standard operating procedures for laboratory technicians. It should also regularly provide trainees with on-the-job training under the direct supervision of experienced laboratory technicians (9). Especially in view of the success of proficiency testing programs as described above, laboratory supervision carried out by staff from the national and/or supranational reference laboratory should contain a strong educational component to guarantee continuous on-site training and education on the peripheral level. The GLRA is presently developing a strategy for standardised laboratory training in the GLRA supported TB control programmes.

Conclusion

The findings obtained by several pilot studies on laboratory supervision and external proficiency testing in Uganda revealed and confirmed the need to monitor and improve the performance of peripheral microscopy units. Therefore, GLRA has been developing a quality assurance programme for peripheral microscopy units under the guidance of the GLRA supranational reference laboratory. It consists of quality control for sputum smear microscopy, standardised laboratory supervision and standardised laboratory training and involves a network of national/regional reference laboratories as well as the supranational reference laboratory in Germany. After first encouraging experiences in Uganda, the components of that quality assurance programme are going to be implemented in other GLRA supported TB control programmes.

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MEASURES TO PREVENT TB TRANSMISSION IN HEALTH CARE FACILITIES

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Risk of TB Infection among Health Care Workers

It is well known to health workers that they have an increased risk of getting into contact with infectious diseases during their work. Any kind of pathogenic bacteria, protozoa, viruses and fungi can be transmitted to them via the usual ways of transmission like contact with blood, through droplets in the air (aerogen) or contact with infective tissues. The majority of infections can easily be prevented, diagnosed or treated. It is important to make sure that they do not cause permanent damage (sequelae) and that effective preventive or curative measures are accessible also in developing countries like vaccination or antibiotic treatment. But the resurgence of Tuberculosis (TB) has caused a lot of reluctance in health workers to work in TB wards or to deal with patients suspect for TB. They consider TB not only to be possibly fatal, but they know that TB may have both disabling effects requiring long term treatment

and socially stigmatising properties. Furthermore this problem of nosocomial infections is aggravated by the risk of acquiring multi-drug resistant forms of TB or even HIV which is completely incurable. An increase of TB infections and diseases in health workers are confirmed in any health care setting in the world where TB prevalence is rising.

From public health institutions in industrialised countries, TB was reported to be the sixth most common occupationally acquired infection among laboratory workers. It has been estimated that health professionals are two to nine times more likely to contract *Mycobacterium TB* than the general public.

Information is limited about the risk of TB transmission to health care workers in countries with a high HIV prevalence, in particular in Sub-Saharan Africa. A study carried out in Malawi found that the rate of TB

infections among nurses working in medical and TB wards was 6,600 per 100,000 - nearly 40 times higher than the case notification rate among the general population in Malawi in 1994 (180 per 100,000). This underlines that the relative risk of health workers acquiring Tubercle Bacilli in specific settings can be up to 40 times greater than that of the general population. Prevention of nosocomial infections is not only a major concern for managers of health care facilities, but it is also an ethical obligation. Rates of transmission in health services appear to be higher, if the diagnosis of TB in hospitalised patients is delayed, when patients do not receive adequate therapy or where there is unrecognised drug-resistance. In the following, practical advice is given that is reasonably effective and can be implemented in low income countries. Furthermore measures are discussed in respect to diagnosis and treatment of infectious TB patients and environmental control in order to protect health workers.

Diagnosis and treatment of infectious TB patients

The most cost-effective method of interrupting the chain of TB transmission is the rapid diagnosis and treatment of infectious patients. There are several ways of insuring as early a diagnosis as possible with the least possible risk of transmission of infection to others.

- adherence to criteria for suspected pulmonary TB (suggested by the national TB control programme or respective TB authorities);
- investigating TB suspects as outpatients, i.e. that all suspects are screened by one office; helpful is the use of an outpatient card register and a laboratory sputum register;
- decreasing delays in sputum collection and delivery of results to hospital wards: one possible solution to these delays is to appoint a ward officer, who follows an explicit list of duties;
- decreasing delays in laboratory smear microscopy; most hospital laboratories stain sputum smear using the Ziehl-Neelsen method and examine for acid-fast bacilli using light microscopy; central hospitals can speed up the diagnosis of pulmonary TB by investing in a fluorescent microscope;

- improving the safety of sputum smear microscopy for laboratory workers: the exterior of sputum containers may be contaminated; laboratory workers should therefore clean the outside of such containers with a suitable disinfectant before opening and processing them. A method to improve the sensitivity of sputum smear diagnosis has been successfully tested in Ethiopia, putting household bleach in the sputum and concentrating the bacteria by centrifugation;
- isolation of infectious TB patients: patients with suspected pulmonary TB can be kept together in one area of the ward, that is screened off from other sections, particularly those occupied by patients with known and suspected HIV/AIDS infection; it is particularly important that infectious patients are isolated from those most susceptible to TB, e.g. immuno-suppressed patients and infants; after treatment, immuno-competent patients with drug-sensitive tubercle bacilli following a shortcourse chemotherapy rapidly become non-infectious (this occurs in about two weeks); to increase safety, it is preferable to continue to isolate all smear-positive patients until they have become sputum smear-negative;
- use of short course chemotherapy for smear-positive, pulmonary TB: short course chemotherapy is much more effective and after two months of therapy, 90 % of patients become smear-negative, irrespective of HIV-sero status; short course chemotherapy should be used wherever possible for all smear-positive pulmonary TB cases.

Environmental Control

One of the most effective measures to reduce TB transmission in health care settings is the improvement of ventilation.

- TB wards and other high risk areas in the hospital: the wards should have plenty of light, many windows that open to the outside and doors to the other parts of the hospital that are kept closed most of the time; exhaust vents that move air from wards to the outside are useful, but may be too costly for many health care institutions; the same principles apply to outpatient clinics and to rooms in which sputum

induction procedures are carried out; ultraviolet light has a germicidal effect on tubercle bacilli, its effectiveness in reducing TB transmission has not been confirmed in practice. UV-lights are also expensive, require proper maintenance and are potentially harmful if not installed properly;

- for working conditions in laboratories: clear guidelines are suggested by WHO and the IUATLD which should strictly be followed.

Protecting the Health Care Worker

First of all, it is important that health care workers must know about TB and about the risk of transmission in health care settings. It can be presumed that knowledge about TB is generally very low. Training and continuous education are a first priority. The measures outlined below should then be considered for personal protection.

- HIV-infected staff should avoid working with TB-patients and TB-specimens: if a health care worker is known to be HIV-seropositive, he or she should be removed to other, safer areas within the hospital; due to stigma and discrimination, voluntary testing may be difficult; another approach is to advise health care workers who exhibit some of the clinical features of symptomatic HIV-infection, to request transfer from high risk environments;
- face masks: special face masks, called HEPA masks, ensure protection against TB by filtering out droplet nuclei of diameter one to five micrometer; however since each mask costs US\$ 5 to US\$ 7, no low income country could afford to use them for widespread TB control in health care settings; standard surgical masks have been developed to prevent the exhalation of particles; while they are effective in doing so, their efficacy in preventing the inhalation of droplet nuclei containing tubercle bacilli of diameter one to five micrometer is less than 50 %; the use of such masks by TB-patients with a productive cough who are being transferred to other parts of the hospital for investigation such as chest radiograms, may help to reduce transmission of the disease; routine use of such masks by staff or ward visitors is not generally recommended, although they may be of some help for staff supervising coughing procedures;
- patient cough hygiene: educating patients to place a hand in front of their mouth when coughing and ensuring that coughing patients are examined with their heads turned away from the health worker, are hygienic measures of unproved benefit, but which are simple to implement;
- screening of health care staff for infection and disease: tuberculin skin testing at regular intervals is controversial because many workers do not comply with screening requirements, the prevalence of true positive tests is low, and in consequence, the cost per case of TB prevented is high; therefore surveillance of health care staff in areas of high TB prevalence by regular tuberculin testing is probably of little value, because many health care workers will already have a positive skin test; regular screening using chest radiographs every six to twelve months is also probably not cost-effective; the most cost-effective way of screening therefore is to follow rigorously the guidelines for screening TB suspects recommended by IUATLD and WHO, and to treat health care workers as soon as active TB is confirmed;
- use of BCG-vaccine: in low income countries, the majority of health care workers will have received BCG-vaccine at birth; the questions then arise whether re-vaccination with BCG confers additional protection against TB, and whether BCG vaccination of adult, HIV-positive individuals is safe. WHO discourages the use of BCG re-vaccination on the basis of lack of evidence for additional protection and concerns for safety; BCG-vaccine can safely be given to children without symptomatic HIV-infection, but it should be withheld from children with clinical AIDS or with symptomatic HIV-infection; at present, BCG-re-vaccination as a means of preventing TB in health care workers cannot be recommended;
- use of Anti-TB drugs like Isoniacid for preventive therapy: trials have shown that Isoniacid given to HIV-infected persons, significantly reduces the annual rate of TB; Isoniacid preventive therapy may rarely be associated with Hepatitis; the risk of complication is generally low, although it is greater for persons over 50 years of age, and for those who are heavy drinkers; at

present, WHO and the IUATLD hold that there is insufficient information to recommend implementation of Isoniacid preventive therapy for co-infected persons, as one of the components of TB-control strategies in programme settings world-wide. Research is on the way to evaluate feasibility and cost-effectiveness.

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APPROACHES TO ADDRESS TUBERCULOSIS IN PRISONS OF LOW INCOME COUNTRIES

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Introduction

Data from several countries reveal that tuberculosis is a problem in prisons. This is due to the fact that the majority of prisoners come from the poor sectors of society sharing a background of unhealthy living conditions. In addition, Tuberculosis (TB) is frequently transmitted among prisoners who, in turn, become a source of infection for the general public, e.g. on the occasion of family visits or after discharge when TB was not cured during stay in prison.

Because of the adverse implications of high TB prevalence in jails for prisoners, staff and the outside community, control programs have been started in prisons. The comparatively "closed setting" of a prison appeared to offer advantages for running a TB Control Program successfully.⁶ However, a closer look reveals a number of problems which need to be tackled before positive results can be expected.

Environmental Factors and Aspects of Internal Organisation Affecting the Occurrence of TB and its Treatment

- Overcrowding is a common feature of prisons often accompanied by poor ventilation. The latter is a special problem in countries with a cool climate where insufficient heating during periods of low temperature urges prisoners to keep windows closed for fear of freezing.

Problems with ventilation get worse, if also laundry is dried in the cells/rooms because it otherwise may get stolen.

- In countries of a generally high unemployment rate, products manufactured by inmates cannot find a market leading to unemployment of prisoners. This automatically increases the time which they spend in their badly ventilated rooms.
- Where revenue from prisoners' production originally had been used for buying essential supplies including medicines, sudden economic decline as experienced by many poorer countries, has a direct impact on food and drug provision as well as maintenance and repair of buildings, further worsening the unhygienic conditions.
- Diet is often insufficient, - either because of economic reasons or because nutritional restrictions are regarded as an adequate kind of punishment. Even if a sufficient diet is provided, repressive relationships among inmates may prevent its just distribution.
- The official power structure represented by the prison administration is accompanied by an unofficial power structure governing culture and affairs among inmates. This unofficial structure comprises of at least three levels: (1) the bosses - professional criminals often with outside connections, (2) the silent majority - those who just serve their term, and (3) the despised ones who may have offended this internal system, may be known as homosexuals (and/or rape

victims within the prison) or may be outcasts from other groups.

- Communication and a certain degree of co-operation between the official prison administration and bosses is essential for any intervention which requires direct participation from the side of prisoners. Yet, the hierarchy among prisoners automatically reduces chances for any inmate of the lower categories to become involved and benefit from any program.
- Regarding the official administration, low salaries, inadequate training and lack of career perspectives easily result in collusion between staff and bosses in criminal activities. This is another reason for a limited access to benefits for certain sectors of the prison population.
- Referrals from one prison to the other happen not only during the period of investigation, but also while serving a long-term sentence. They may be ordered because of
 - (1) issues of internal security and/or overcrowding,
 - (2) lack of food, medical facilities or staff or
 - (3) even promotional reasons on grounds of prisoners' good behaviour. Such referrals hamper attempts for active case finding and lead frequently to interruption or even a complete halt of treatment for chronic conditions, because quality of health services differ between prisons. Respective decisions are often taken without consideration of a prisoner's health or treatment requirements.

Roles and Responsibilities in Service Provision Affecting TB Occurrence and its Treatment

- Prison health services function under the authority of the correctional department, a unit usually attached to the Ministry of Justice. Thus, they are cut off from monitoring and/or support through the Ministry of Health for aspects of surveillance, diagnostic equipment and drug supply, control of standards of care provision, professional promotion and, last but not least, remuneration.
- Normally, the high social status attached to health personnel fuels staff motivation. However, working in a prison environment may carry with it a certain stigma. The comparatively low social reputation

experienced by prison health care providers impedes their motivation to offer quality services.

- Prison health services have an ambiguous role to play: on the one hand, they are regarded by prisoners as representative of the system which is responsible for their detention; on the other, they are the first port of call for health problems and the gate keepers for access to certain benefits on account of a medical condition. Mutual trust between health service providers and prisoners cannot easily develop in such a situation.
- While TB is a widely dreaded disease also among prisoners, there is an abundance of even more immediate concerns for them. These are in the forefront, often so much so that infection with TB may be actively sought in order to get the benefits of treatment. The diagnosis of TB may permit to receive more nutritious meals or stay in the hospital for a few weeks. It will also entitle to receive drugs. Even if these are provided under strict observation, prisoners know techniques to avoid swallowing them. After return to their rooms, they may be kept for "sale" to guards in exchange for goods or some floor space to sleep on.
- On the other hand, there may be also an occasional influx of TB drugs organised by the bosses through their outside connections. These drugs are considered more effective than those offered by the prison health services. This leads to inconsistent treatment with its known consequences for development of MDR-TB.

Open Questions

An understanding of the above mentioned factors, which are typical for a prison situation, asks for TB control measures which address issues well beyond the medical realm and/or consistent implementation of the DOTS strategy. The following are important issues to be addressed:

1. It is essential that certain restrictive measures necessary for TB control are adopted and consistently implemented. This will be the case only if interests between providers and patients concur well enough to override concerns about personal autonomy of patients.

- Will it be possible to agree on a TB control program in prisons looking at the differing interests of people who would need to co-operate in such a program?
 - What ethical implications has it if such a program is carried out in an environment of coercion?
2. It is essential for all TB programs to fuel and maintain motivation for high quality performance of providers and patients alike.
- What can be done to improve the situation regarding training and supportive supervision?
 - What immediate priorities need to be met before a true concern regarding TB control can be expected?
 - Whose message will/can prisoners trust?
3. It is essential to secure a continuous, adequate supply of anti-TB drugs as well as necessary laboratory equipment.
- What needs to be done, if responsibility for the control program lies with a governmental department usually not involved in dealing with issues of health service organisation?
 - Is the suggestion to integrate prison health care with the health priorities of the Ministry of Health really a valid option in view of the notorious difficulties with inter-departmental co-operation? Which department, for example, will make the final decision in regard to referral of prisoners when referral is likely to result in incomplete treatment?
4. It is essential to provide the required TB drugs consistently.
- Will it ever be possible to interrupt the "black market for TB drugs" which is organised through the unofficial system with collusion of guards?
- Who within the materially disadvantaged population of prisoners and guards can be expected to understand the negative impact of such practices on (public) health and make it a personal priority, if even well-off members of the mainstream society are not ready to adhere to DOTS on grounds that this would mean to sacrifice immediate material gains from their well paying patients who ask for new, more potent drugs?

Conclusion

TB control requires an assessment of priorities of different stakeholders and adaptation of messages and measures to meet immediate needs. Providing enough buildings or a balanced diet may be part of it. In addition, an adequate answer could also require a review of responsibilities in respect of areas of conflict in administrative interrelationships, which may gain from more flexible approaches. Even a review of legal codes and practices may be necessary, e.g. in regard to the adequacy of punishment in view of its risky implications. In many countries, Church related organisations enjoy already established contacts with prisoners and official administration through their prison apostolates. Some of them are even involved in prison health education. They are especially well placed to address these burning issues and should be encouraged to reconsider the potential role they could play by co-operating with the public administration in this difficult field.

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BRIEF HISTORY OF TB

Adapted from the NJMS National Tuberculosis Centre, USA
University of Medicine and Dentistry of New Jersey, Newark

The Ancient World

Mycobacterium TB (TB) has been present in the human population since antiquity - fragments of the spinal column from Egyptian mummies from 2400 BCE show definite pathological signs of tubercular decay.

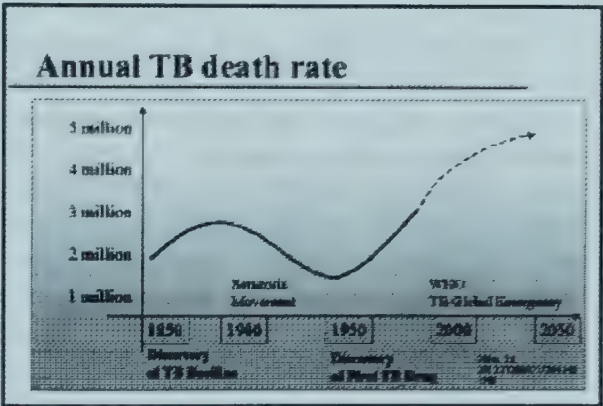
The term phthisis, consumption, appears first in Greek literature. Around 460 BCE, Hippocrates identified phthisis as the most widespread disease of the times, and noted that it was almost always fatal. Due to common phthisis related fatalities, he wrote something no doctor would dare write today: He warned his colleagues against visiting cases in late stages of the disease, because their inevitable deaths might damage the reputations of the attending physicians.

Exact pathological and anatomical descriptions of the disease began to appear in the seventeenth century. In his Opera Medica of 1679, Sylvius was the first to identify actual tubercles as a consistent and characteristic change in the lungs and other areas of consumptive patients. He also described their progression to abscesses and cavities. Manget described the pathological features of miliary TB in 1702. The earliest references to the infectious nature of the disease appeared in seventeenth century Italian medical literature. An edict issued by the Republic of Lucca in 1699 states that, "henceforth, human health should no longer be endangered by objects remaining after the death of a consumptive. The names of the deceased should be reported to the authorities, and measures undertaken for disinfection."

In 1720, the English physician Benjamin Marten was the first to conjecture, in his publication, A New Theory of Consumption, that TB could be caused by "wonderfully minute living creatures", which, once they had gained a foothold in the body, could generate the lesions and symptoms of the disease. He stated, moreover, "It may be therefore very

likely that by an habitual lying in the same bed with a consumptive patient, constantly eating and drinking with him, or by very frequently conversing so nearly as to draw in part of the breath he emits from the lungs, consumption may be caught by a sound person. I imagine that slightly conversing with consumptive patients is seldom or never sufficient to catch the disease." For the early eighteenth century, Dr. Marten's writings display a great degree of epidemiological insight. In contrast to this significant level of understanding about the aetiology of consumption, which was already enabling prevention and a break in the chain of infection, those attempting to cure the disease were still groping in the dark

Figure 5:



The Sanatorium Movement

The introduction of the sanatorium cure provided the first real step against TB. Hermann Brehmer, a Silesian botany student suffering from TB, was instructed by his doctor to seek out a healthier climate. He travelled to the Himalayan mountains where he could pursue his botanical studies while trying to rid himself of the disease. He returned home cured and began to study medicine. In 1854, he presented his doctoral dissertation bearing the auspicious title: Tuberculosis is a Curable Disease. In the same year, he built an institution in Gorbardsdorf where, in the midst of fir trees, and with good nutrition, patients were exposed on their balconies to continuous

fresh air. This setup became the blueprint for the subsequent development of sanatoria, a powerful weapon in the battle against an insidious opponent.

Detection of the Germ

New advances then followed in rapid succession. In 1865, the French military doctor Jean-Antoine Villemin single-handedly demonstrated that consumption could be passed from humans to cattle and from cattle to rabbits. On the basis of this revolutionary evidence, he postulated a specific micro-organism as the cause of the disease, finally laying to rest the centuries-old belief that consumption arose spontaneously in each affected organism.

In 1882, Robert Koch discovered a staining technique that enabled him to see *Mycobacterium TB*. What excited the world was not so much the scientific brilliance of Koch's discovery, but the accompanying certainty that now the fight against humanity's deadliest enemy could really begin.

The measures available to doctors were still modest. Improving social and sanitary conditions and ensuring adequate nutrition were all that could be done to strengthen the body's defenses against the TB Bacillus. Sanatoria, now to be found throughout Europe and the United States, provided a dual function: They isolated the sick, the source of infection, from the general population, while the enforced rest, together with a proper diet and the well-regulated hospital life assisted the healing process.

These efforts were reinforced by the observation of the Italian Forlanini, that lung collapse tended to have a favourable impact on the outcome of the disease. With the introduction of artificial pneumothorax and surgical methods to reduce the lung volume, the depressing era of helplessness in the face of advanced TB was over, and active therapy had begun.

A further significant advance came in 1895 when Wilhelm Konrad von Roentgen discovered the radiation that bears his name. Now the progress and severity of a patient's

disease could be accurately followed and reviewed.

Another important development was provided by the French bacteriologist Calmette, who, together with Guérin, used specific culture media to lower the virulence of the bovine TB bacterium, creating the basis for the BCG vaccine still in widespread use today. Then, in the middle of World War II, came the final breakthrough, the greatest challenge to the bacterium that had threatened humanity for thousands of years - chemotherapy.

A History of TB Chemotherapy

In fact, the chemotherapy of infectious diseases, using sulphonamide and penicillin's, had been underway for several years, but these molecules were ineffective against *Mycobacterium TB*. Since 1914, Selman A. Waksman had been systematically screening soil bacteria and fungi, and at the University of California in 1939 had discovered the marked inhibitory effect of certain fungi, especially actinomycetes, on bacterial growth. In 1940, he and his team were able to isolate an effective anti-TB antibiotic, actinomycin; however, this proved to be too toxic for use in humans or animals.

Success came in 1943. In test animals, streptomycin, purified from *Streptomyces griseus*, combined maximal inhibition of *Mycobacterium TB* with relatively low toxicity. On November 20, 1944, the antibiotic was administered for the first time to a critically ill TB patient. The effect was almost immediately impressive. His advanced disease was visibly arrested, the bacteria disappeared from his sputum, and he made a rapid recovery. The new drug had side effects - especially on the inner ear - but the fact remained, MYCOBACTERIUM TB was no longer a bacteriological exception, it could be assailed and beaten into retreat within the human body.

A rapid succession of anti-TB drugs appeared in the following years. These were important because with streptomycin monotherapy, resistant mutants began to appear within a few months, endangering the success of antibiotic therapy. However, it was soon demonstrated

that this problem could be overcome with the combination of two or three drugs.

Chemotherapy Today

Following streptomycin, p-aminosalicylic acid (1949), isoniazid (1952), pyrazinamide (1954), cycloserine (1955), ethambutol (1962) and rifampicin (1963) were introduced as anti-TB agents. Aminoglycosides such as capreomycin, viomycin, kanamycin and amikacin, and the newer quinolones (e.g. ofloxacin and ciprofloxacin) are only used in situations of drug resistance. Combinations of a B-lactam antibiotic with a B-lactamase inhibitor enhance treatment effectiveness, but the newer drugs, including the macrolides, have not received much clinical testing.

Two properties of anti-TB drugs are important: antibacterial activity, highest in isoniazid, rifampin or streptomycin and their capacity to inhibit the development of resistance, the most effective drugs being isoniazid, rifampicin and ethambutol.

With the proper four drug regimen, there should be a rapid clinical improvement and a significant fall in the bacterial count. After a month, the patient should be afebrile, feel well and have regained weight. Coughing and sputum should have diminished and improvements visible on the X-rays. Although bacteria will still be present in the smears, they will become more and more difficult to culture. Improvements will be visible on the X-rays for three to four months. If the disease was initially severe, though, the end of treatment may not be reached for a year.

The absence of radiological improvement in the first three months should be grounds for concern and indicate that a change in therapy is needed. Patient compliance and the bacteria's drug sensitivity should be re-evaluated. Relapses usually occur within six months of the end of treatment, and in most cases are due to poor patient compliance. Patient compliance must be monitored throughout treatment; this is done at the National TB Centre through directly observed therapy.

When TB becomes active again in a previously treated patient, there is a high chance that the bacteria will now be drug resistant. Any

current therapy must be suspended until multiple drugs are found to which the pathogen is fully sensitive, and treatment can be resumed with the addition of these drugs to the original regimen. Never add a single drug to a failing regimen. If the micro-organism is resistant to the standard drugs, then it will be necessary to administer more toxic medications such as ethionamide, prothionamide, pyrazinamide, cycloserine, capreomycin, viomycin or kanamycin.

The Recent TB Epidemic

The registered number of new cases of TB world-wide roughly correlates with economic conditions: the highest incidences are seen in those countries of Africa, Asia, and Latin America with the lowest gross national products. WHO estimates that eight million people get TB every year, of whom 95% live in developing countries. An estimated 3 million people die from TB every year.

Figure 6:

Tuberculosis - global epidemiology			
Region	Incidence rate (.../100,000)	Mortality	Rate of Infection
South-East Asia	247	35%	1.0-2.5%
Africa	293	40%	1.0-2.5%
Latin America	120	20%	0.5-1.5%
Eastern Europe	48	15%	no data %
Industr. Countries	24	7%	0.01-0.1%

Quelle: Dueddel 1996

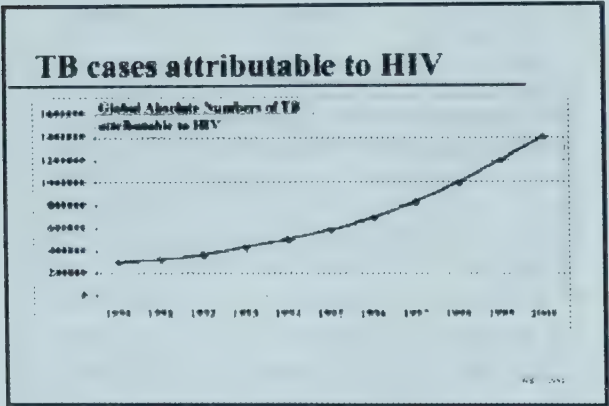
In industrialised countries, the steady drop in TB incidence began to level off in the mid-1980s and then stagnated or even began to increase. Much of this rise can be at least partially attributed to a high rate of immigration from countries with a high incidence of TB. It is also difficult to perform epidemiological surveillance and treatment in immigrant communities due to various cultural differences.

A great influence for the rising TB trend is HIV infection. Chances are that only one out of ten immunocompetent people infected with MYCOBACTERIUM TB will fall sick in their lifetimes, but among those with HIV, one in ten per year will develop active TB, while one

in two or three tuberculin test positive AIDS patients will develop active TB. In many industrialised countries this is a tragedy for the patients involved, but these cases make up only a small minority of TB cases. In developing countries, the impact of HIV infection on the TB situation, especially in the 20-35 age group, is worthy of concern.

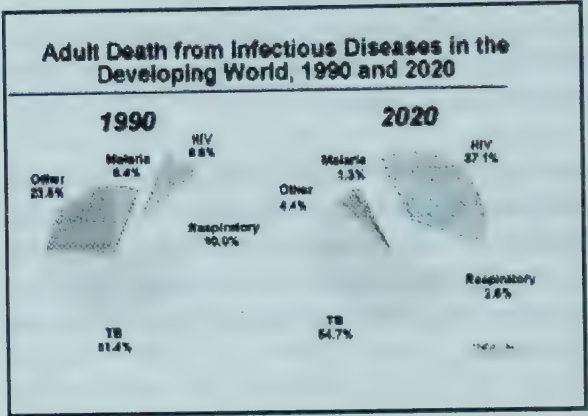
A final factor contributing to the resurgence of TB is the emergence of multi-drug resistance. Drug resistance in TB occurs as a result of tubercle bacillus mutations. These mutations are not dependent upon the presence of the drug. Exposed to a single effective anti-TB medication, the predominant bacilli sensitive to that drug, are killed; the few drug resistant mutants, likely to be present if the bacterial population is large, will multiply freely. Since it is very unlikely that a single bacillus will spontaneously mutate to resistance to more than one drug, giving multiple effective drugs simultaneously will inhibit the multiplication of these resistant mutants. This is why it is absolutely essential to treat TB patients with the recommended four drug regimen of isoniazid, rifampin, pyrazinamide and ethambutol or streptomycin.

Figure 7:



While wealthy industrialised countries with good public health care systems can be expected to keep TB under control, in much of the developing world a catastrophe awaits. It is crucially important that support be given to research efforts devoted to developing an effective TB vaccine, shortening the amount of time required to ascertain drug sensitivities, improving the diagnosis of TB, and creating new, highly effective anti-TB medications. Without support for such efforts, we run the risk of losing the battle against TB.

Figure 8:



Revised: July 23, 1996 URL: <http://www.umdnj.edu/~ntbcweb/history.htm>

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THEOLOGICAL REFLECTIONS IN RESPECT TO TUBERCULOSIS AND HIV/AIDS

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The Experience of People

I come to you at the end, when you have had enough really, and I am going to confuse it even more by taking the stands of a theologian, somebody who is reflecting on what has been said and what is happening in this area and the point of view of our Christian faith, our belief in God. First of all, it is not easy of course to get even any adequate idea of what is going on. But if theologians do not come to it, to the experience of people, and somehow take it into their own experience, I do not think they can reflect very effectively on what it means in the life Christian faith.

I was drawn into the HIV/AIDS issue about 9 or 10 years ago by Caritas Internationalis as the member of their Task Force. But I have a lot longer experience of Tuberculosis. At the age of 13, I buried three close members of my family to Tuberculosis. They were a very close uncle and aunt and a very close first cousin. And at that time in the 1930's and 40's and in the 50's, Tuberculosis had much of the status that I saw HIV/AIDS taking on in our own country and in many countries, subsequently. So it was something of a shock to find, when we thought Tuberculosis had been finally wiped out as it were, to find it coming back and to find it in this deadly combination with HIV/AIDS, a kind of a dual death blow.

Causes as expression of commitments

In trying to frame my theological reflections, I followed the structure, that we had been given in the working groups. It seems to me that we people here are people with commitments, but it is not true by and large, that baptised and believing Christians are noted for their commitments. We have many people who see themselves as adequate Christians, perhaps some mass goers or service goers, but who do not feel any great sense of a Christian commitment to the neighbour or to the world at large. And the way this is translated for most

of us in the course of our lives, that kind of commitment is in terms of what I am calling here "causes", that we adopt certain causes as expressions of our Christian commitment, particularly to the neighbour or indeed to the world at large. So that we people here, I think are by and large, people who have causes, whose commitments take on a defined connection with some particular issue, which we wish to promote as an expression of our love of neighbour, our love of God, of our faith in that sense. So that these commitments are made of what they manifest, they become more effective at manifesting causes. And all of you in a way have been involved in many causes as I said. These causes in particular have to do with human development and with health care.

But let us reflect for a moment on how causes express and define our commitments. Our commitment to God is what we mean by faith, but which is difficult enough to pin down. That is in the approach to the neighbour or to the world, to the creation that we find expression for our commitment to God. That approach to the neighbour takes as I say many different throngs. We think of it perhaps first of all, in terms of relationships, rather than causes. But as the relationships respond to a large group of people, they become in a sense causes rather than simply relationships. We may be committed and will be committed, we hope, to our family and our friends, but in the larger world, we need to express thus to some organised understanding of the needs of people and through some organised response and in that sense we become people of causes.

Now causes have a certain agenda. We take it out of ourselves, we give ourselves to the service of some deprived or otherwise needy group. In that we feel we are following the example of Jesus Christ, indeed the example of God's self, for God committed God's self to the cause of humanity, to the cause of creation. But sometimes we can become prisoners of the

causes, in a sense that we need to be people of multiple and different causes. There is a danger that we could become prisoners of a single cause and every cause has its ambiguities, because in the focusing on the particular cause, we may be on one hand excluded from our commitments altogether, a range of related or associated causes, why it is important for instance, to see now the connection between HIV/AIDS and Tuberculosis. It may also mean that as we ignore or exclude certain other causes, that we become in the service of a particular cause, relatively unscrupulous in our means of pursuing. I do not want to make too much of this, I found no evidence of it at this Conference, but simply to let it be clear, that the splendour of causes carries with it an ambiguity, as does indeed all human effort.

Seeking for the Fulfilment of the Human Family

But to push on into the development and health causes which concern us, we have to and do recognise of course, that these causes in many ways have been pursued over the centuries. And that within our own community of the Church, causes like hospitality, care of the sick, relief of poverty etc., if not always pursued in an effective and structured way, have yet been part of the Christian commitment over the centuries. If we are to think of 2000 years of Christianity, we must think that there were 2000 years of these kinds of commitments and causes. In particular, the idea of development, of development of the whole person and of the whole human community is something that comes naturally to people who believe in one God, who believe that God is a loving God, who believe in one human family, who believe that human family was created for fulfilment by the one God, that that development commitment of ours comes naturally, or should come naturally to us. It does not of course get exercised easily and persistently by many of us, but there is no way of reflecting on the world in the light of our Christian faith and not recognising somehow, that this is our commitment to the fulfilment of the human family in the earth on which we live. That is in one way what has been called "salvation" or "liberation" or "transformation" or "redemption". The overcoming of the limitations and the difficulties for the emergence of this one flourishing human

family, the overcoming of that to the persistent hearing of God and the persistent calling of us to exercise on God's behalf that care and commitment.

Healing as the Root of God's Relation to Humanity

And of course in the particular situation in which we are as focusing on health care, we see that the healing work itself is deeply rooted in our understanding of God's relations with humanity. It may seem extraordinary and we might come back to this, how God should create a humanity and a world that is good, and yet from the beginning, it has being a need of healing. This is one of the paradoxes of our existence, that we are good and yet in need of healing, that all our lives we will be in need of healing. Indeed every thought of care we offer and love we offer to people has first of all some healing dimension to it. It has other dimensions, enriching and transforming in other ways. That healing is central to it, at least as far as we understand the world in which we live, which again, like Jon was saying this morning, about the humility we need, we will always be in need of healing. With the best programme of medical care in the world, there will be many levels of healing, that everybody will need including, and perhaps above all, the "would be" healers themselves, so that this is part of our understanding of our cause to the healing, the healing of the obviously ill, of the healing of the hidden ills that effect us all.

Cause of Jesus, God's Cause

In pursuing this a little more in terms of Christian meaning, we have to go back again to the mission and commitment and what has been called particularly in German, the cause of Jesus, God's cause was Jesus' cause. God's commitment to the healing and transformation of humanity and the world was Jesus' mission, Jesus' commitment, Jesus' cause. That is how we read the New Testament and it is worth looking at it in terms of how God set about that and we had two striking readings this morning of Jesus' own mission in Luke 4, but in a way even more challenging and radical, the peace from Philipians, where God as in Jesus emptied himself, became one of us. It is that absolute surrender to the human condition, to the creaturely condition by the Creator God in

Jesus, that is the most radical piece of strategic thinking by God. The centuries in which God had worked with the people of Abraham and so on, God was for the most part the distant and the dominant and the Lord, but in the person of Jesus, God surrendered all that Kingship, that Lordship, to become a simple, humble, weak, vulnerable human being. That is at the heart of our strategy in response to our causes where the causes are about development and healing of people, that we have to surrender to bare reality, we have to let ourselves become, in that Jesus' fashion, one with them.

Of course, we can see how this worked out with Jesus and the way many of you are trying to work it out. How he set about forming this new human community by attending first of all to the ill, to the hungry, to the so-called sinners, to the excluded, to the poor. This was the message we got from Luke's gospel and the message of the whole ministry of Jesus. If the strategy is the surrender of the power and the majesty of God to become that kind of vulnerable human being and that kind of vulnerable human being seeking to establish the new communion, the new fellowship with the people who are most excluded and most vulnerable.

Be Prepared for the Destiny of Jesus

So what we want therefore, is our efforts to succeed. We set about that in a systematic and intelligent way, but we have no guarantee. We have to be prepared for the destiny of Jesus in a certain sense, of dying in disgrace and failure. This is part of what we have to take on ourselves in this kind of work. Jesus did not seek it. What he sought was the care of the people, the service to them, and the development of the new community. But this is how it worked out in his particular case and we have to be ready for that kind of failure, too. But as we do this of course, we do not do it as individuals. One of the difficult things for us to recover in Western thinking and in Western theology, is a true sense of community. We move on therefore to our structures and we move to the question of the Church as community. In that thinking, we have to recognise that what Jesus established had again many aspects to it. But one of the essential features really, was that he established a community of equals, this was part of the

thrust of the strategy of God becoming one, of Jesus seeking out the deprived and the excluded, so there would be no doubt about the equality of relationship or partnership that would be established. It is something that as Church, we have to think about more seriously, because we have our structure limitations in terms of the actual external structures and the mental structures with which we operate.

Development of communities and friendships

One of the ways of overcoming the almost ideological and abstract notion of equality, is to recognise that what Jesus established was a company of friends and this company of friends is again what we as a community have to develop. We develop it by attending, say some of the more likely friends, and we develop it by establishing in the world as a whole, as witness to the capacity of human beings, in friendship, growing in intensity and extension, that it is a wave, a force that iminates from us and from our Church to establish the whole world as that company and friend. Because in the theological understanding of the Church, particularly as it was expressed at the Vatican II, on the one hand it is a manifestation of the mystery of God, the mystery of this God we have seen seeking us out, becoming cosmic as well as Creator, becoming human as well as divine. It is a manifestation of that on the one hand, but it is also a manifestation of the potential of the human community to be one community, in which we all participate as equals with that bonding that friendship at its different levels and different degrees brings with it.

What is of course remarkable about friendship as opposed to family is that friendship is clearly between people who are different and other, that in the course of our lives, we hope to become friends with our families, but we also recognise, that the friendship's reach is much broader and that it takes into account and cherishes difference. It is about being different and yet being bonded. That is something that our community, here, this Conference, that our work is about. It is about the bonding of the different in the friendship that is finally rooted in Christ and in God.

The Ambiguity between the Human and the Cosmic

That bonding of the human community we see increasingly in the bonding with the living community on the planet with the whole cosmos. So that there is in fact an important way within the Church as we read of course in the Godly mission of Jesus himself, it is also about the community of creation, not just about the human community. Indeed we know that in terms of our western isolation at certain stages from the community of creation, that was maintained in other civilisations much more strongly. This was partly to do with the ambiguity of Christianity about the relationship between the human and the cosmic. We cooperate, we cooperate with one another and we cooperate in the service of the different dimensions of each community and each person, so that that kind of integral vision of the person and integral service of the person that we were talking about in our workshop and certainly in many others and is typified now by bringing together Tuberculosis and HIV/AIDS as it seems to me, that that is part of the kind of bonding which involves inclusivity, participation in the area we are talking about and it is the bonding that was established between God and humanity, between God and creation, at the price of the life and death of Jesus Christ. That is the sense of structure that we are moving towards. It does mean that in our service of Tuberculosis and HIV/AIDS, we bring to it that kind of affective character and that we also bring to it a freedom to cooperate with whoever is co-operating in this area, that we do not have ideological hang-ups. The point is that the God who bonded with us and with creation is now enabling us to bond with the people in this kind of distress and the people who would serve them.

Divine and Human Operations

The operations have been divided by me into human and divine. The critical one seems to me, for both the human and the divine, is called working with nature. It is part of the human and medical tradition, it is part of the Christian tradition that we cooperate with the creation of God, the working with nature. As I move into the human working with nature, I want to take a slightly strange step and I want to talk about nature under three different headings. We will be the people that will be

working with, it is the same nature, but we have different focuses, with different ways of dealing with it at different times.

The Nature of Science

First of all, let me talk about what I call the nature of science or the nature science works with. That nature comes to us whether to the telescope or the microscope etc., it comes to us in a most extraordinary way as intelligible, that we can understand its operations and we can work with it. At the same time we know and trust that nature will continue to give up its secrets in important ways, that there is a continuing intelligibility about it which a one-time physicist myself, I find remarkably exiting.

I have had the benefit over the years of listening to Jon Fuller reporting on the latest stage of investigation into the causes and hopefully possible cure of AIDS and the amount of new information that emerges that fits into a wider context and the intelligibility that it reveals is quite extraordinary. It is not simply about statistics, important as there are, there is a patron that we can uncover, that fits with the human mind in a most extraordinary way, and that intelligibility is at the heart of science. It is that which enables us in more applied science to manipulate, to move it around, to interfere, to improve, to deal with disease and so on. That is one of the remarkable features of the development of modern science.

We have to recognise that there are limits to this, limits in what we know, because knowledge comes along or breakdown of the system we have developed on that basis. Those kinds of limits induce in the best of our scientific thinking a definite humility and a definite attitude of that we will never just be masters. If we seek to master we end up destroying. There is a sense in which we sell nature by seeking to understand it, rather than master. Master is an old word in the western tradition for understanding something, but it had dominance, exploitation and so on, which we have to stand back from. We began to stand back from it seriously in the west with the explosion of the atomic bomb. That was the first thing we realised that we are not going to master nature, it is something that has pushed

us back from there. That induces in a sense an attitude to nature, which I would call the nature of morality. It is not that sciences are immoral, but in their focusing immediately, it is only at the limits that we come aware of the moral.

The Nature of Morality

The nature of morality is the nature to which we have to be responsible. The nature of morality is a nature for responsibility. It is nature for care, indeed, it is a nature for befriending. Ideas that really do not come into our scientific vision of nature, so that it is that nature, that takes us to the stage of putting our medical research and our medical treatment and so on, HIV/AIDS, Tuberculosis as well as all the others, into what we call sometimes a "human" context or a "moral" context, so that at that stage we see how e.g. the moral commitment, the cause we have taken up as a moral cause, into which we want to integrate all the scientific knowledge we can acquire, is qualified by that sense of responsibility, but also the commitment to those people with this particular need, to share with them, the commitment of compassion, of suffering with them.

It is in that, indeed, that so much of the work of groups like this is done, and much of that fuels some of the best scientific work, particularly in medicine. But it is the nature that belongs to the moral human being that in fact elicits from us that attitude of compassion.

The Nature of God

Let me say a brief word about that kind of nature, the nature of science, the nature of morality simply, the nature of God. The nature that God created, the nature that we belong to, that nourishes us, that threatens us, that we are called to celebrate. Celebration is not a natural scientific attitude, not a natural attitude, it is a larger human attitude, indeed it belongs to recognising the gift of nature and implicitly it seems to me, the giver of nature. It is that openness often celebrated in poetry and art and so on, that offers us our final connection with nature and that is the connection of contemplation, of prayer, of worship. That is the nature of God that we are in touch with.

God's Cause: the Healing of People

Now I want to talk more briefly and naturally more ignorantly about divine operations. It is an odd word to use, but as we had this kind of framework, I thought we ought to look at it. We had been talking about it in many ways already. For us with our sense of creation as gift, we recognise that the creating God is not somebody who has abandoned creation, and therefore, as we move towards the creation of God and then have some sense of the creating God, we will be alert for the continuous creating activity. The continuous creating activity of course, is again an expression of God's commitment, of God's love, of God's cause to the healing of people. So that as we approach it medically, socially and personally etc., we will know that there is a larger force at work here, if we could tap into it. That there is a resource of love and healing that we will need to attend to, that may come to us in odd fashions, and will of course be mediated through humanity and through nature.

It will not come like a blinding lightening or like a particular injection. But it is that alertness to the final mystery of these particular people, and that mystery as sustaining them and healing them, of transforming them, that seems to give a further and richer quality to how we respond to people with HIV/AIDS or Tuberculosis or whatever it might be.

As we do that, we come into that presence and power of the mystery we call God. We come into what we have called in the past "the Kingdom" or the "Reign of God", which we pray for in the Our Father, which all our work is geared towards, which as Church, we assign at least partial realisation of, and which we endeavour to let emerge in all the possible ways through medical science, through art, through politics, through economics. Whatever it might be, that the reign of God will emerge.

The Risk of God

But in doing that of course, we are again as in the expression of Jesus whose preaching was about the reign of God, we are putting ourselves at risk. We might just reflect upon the risk God has taken in entering into this whole, maybe crazy enterprise of creating a world distinct from God's self, of allowing and

enabling to emerge in that world, people who are free to recognise and respond or to reject and who persisted in the faith of rejection to establish a loving communion with them and between them. But that is the kind of risk God took, that is the kind of risk he sent his own son, saying they will spare my son.

We know what happened to the son, which showed that God was not a person who calculated risks. But that risk, that God takes, is part of what enables us to move out of ourselves. In this kind of work and in the early days I worked with the HIV/AIDS people, we had great kind of emphasis on persuading people that you could not get HIV/AIDS from caring for them. People had all these fears, and now we are in a position, if it combined with Tuberculosis, you are in a very different situation as far as care is concerned. How do you protect health carers? There are risks involved, risks that have to be shared and risks that have to be reduced.

Community with God

But it is in the end about establishing, particularly for the most vulnerable and the most vulnerated, if one may use that word, where we have to risk ourselves, it is were God risks God's self and in the end, the reign of God, where the communion in God will emerge for all of us. I believe that kind of work you have been doing and will be doing in the future is a remarkable contribution to enabling human communion with God, earthly communion and God to emerge for us, not now, not in history, but finally and fully through Christ.

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RÉSUMÉ OF THE CONFERENCE ON TB AND HIV/AIDS

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Problem Outline

In the last decade, the HIV pandemic has contributed to the already worsening health problem of Tuberculosis. The most important factors responsible for the increase of both epidemics are man made like changes in the social context and growing poverty leading to migration. This goes together with the deterioration of the health care infrastructure in many countries and the fact that sometimes TB control programmes are poorly managed or under funded. Nowadays no country lives in isolation, and the health problems of each will sooner or later have an effect on others. There can be neither a tuberculosis-free nor an HIV-free oasis anywhere in the world. We are all concerned and are asked by the infected and affected to work for a global response.

An observed lack of commitment is due to basic obstacles such as:

- lack of good epidemiological data on each of the dual epidemics
- lack of professional consensus about cost-effective approaches to TB control, STD control and HIV containment and
- reluctance to monitor effectiveness (coverage and outcome) of ongoing TB and HIV/AIDS programs

Situation Analysis

HIV and TB programmes usually function separately from each other. Both infections have a mutual enhancing impact on each other and thus on the respective control programmes:

- All programmes have to deal with an increased number of patients.
- Problems arise in respect to diagnosis.
- Treatment becomes more complicated.
- Despite all efforts, morbidity and mortality will increase.
- Stigma will be experienced by a wider group of people. This affects adversely health seeking behaviour and the adherence to treatment.
- The risk of nosocomial and institutional transmission has a negative impact on staff motivation.

Diagnosis and cure of Tuberculosis should be a concern in any case of symptomatic HIV infection, because TB is a major cause of morbidity and mortality for PWAs. Despite all constraints, considerable opportunities for synergy between TB and HIV programmes do exist. Decentralisation and the increasing autonomy of districts which health sector reform is bringing to many countries, should be used as an opportunity to enhance the concerted management of the dual epidemics. Possible actions include: training; community care; IEC manuals and guidelines; advocacy; surveillance; collaboration with NGOs; and social mobilisation.

Concepts enhancing Synergy

What are the potentials for synergy between TB and HIV programmes? Real progress in controlling TB and providing care for HIV can only be achieved with a dual strategy targeting both epidemics: **TB control and HIV prevention**. This will first require gathering the resources needed for action. Requirements for successful programmes at local level, which must be checked for their feasibility, are:

- reinforcement of management and technical support capacity of teams situated at the intermediate level
- patients' access to the following: to a quality controlled laboratory in an appropriate and an acceptable distance (e.g. less than 20 kilometres), affordable

drugs with payment schemes reinforcing adherence and smear examinations during treatment, continuous availability of TB drugs,

- the presence of qualified health care providers: trained, paid, supervised and
- the accountability of health care providers.

The continuum of care model can assure comprehensiveness, integration, continuity and accessibility of care. Strengthening of this model and its components at all levels can make cure possible in many settings which are out of reach for vertical programmes. Providing care for Tuberculosis patients in the community has the potential to reduce patient load on hospitals and health centres, decrease costs to patients and their families, improve adherence by making treatment more accessible and reduces the risk of nosocomial transmission to health care workers and other patients. Community care organisations are the cornerstone of the continuum of care model. Therefore their contribution is of vital importance.

However their involvement is not a 'magic bullet' and does not lead easily to a success. Community based organisations supported by church related organisations very often fall short of internationally recommended standards. Shortcomings may arise from the charitable and compassionate attitude to provide moral support and palliation for an incurable disease, the lack of knowledge, the fear of Tuberculosis and the failure to recognise its clinical and epidemiological importance for HIV/AIDS patients. Further problems which arise with the use of community health workers are lack of sustainability due to high turnover. In developing and fast developing countries there is a need to explore new ways of providing care for Tuberculosis patients based on community participation. Ways must be found to address the following issues:

- the establishment of a close co-operation between national TB control programmes at district level, hospitals, health centres, and community care organisations,
- the integration of a national TB control programme system of registration, recording and reporting into community care organisations,

- the development of training methods and materials for community health workers,
- the development of a supervision system of community health workers,
- training for a high level of motivation of community health workers,
- the supply, storage and delivery of drugs
- incentives to motivate community workers to stay in the programmes
- imbalances of power between the professionals and the volunteers

Lessons of capacity building which have been learned in 'HIV/AIDS work' during the last two decades may overcome blockages in TB control programmes in respect to health seeking behaviour and adherence to treatment. Church institutions have a specific experience to share in this respect. It is important that new alliances between public services and non-governmental services assure that the challenges of cure and care are met in the future.

Conclusion

Real progress in controlling Tuberculosis and providing care for HIV can only be made with a dual strategy targeting both epidemics. Control of TB means curing patients, and HIV prevention means not only assurance of blood safety, cure for opportunistic infections and sexually transmitted diseases, but also health education, capacity building, legal and spiritual support.

COMPILATION OF THE OUTPUT OF THE WORKING GROUPS

Organising Committee of the Conference

What should be done?

- Donor agencies, implementing agencies and communities need to recognise and respond to AIDS/TB as major, inter-related problems
- Creating a network of deciders, donors at different level; they need to develop good co-ordination between them
- Networks at international and local level are needed
- Strengthen responsibilities of the deciders and the church responsibilities at national and local levels
- Sensitisation of bishops and priests on HIV-TB problem
- Strengthen awareness of desk officers about the health program to obtain better decision-making
- To co-ordinate and define a common policy
- Long-lasting support from donors, this means to revise the concept of sustainability
- Development agencies need to provide both TB drugs and technical support
- A different public health vision is needed which is not only concerned with cure but with care and prevention.
- Aiming at integrated health care package
- Situation analysis needs to be done in each country
- It is necessary to better define what HIV and TB have in common or not to know better the activities (to be integrated or not)
- Community-based initiatives as a priority (strategy)
- Capacity-building-empowerment of communities

- To improve quality of care in CBO's
- To circulate materials (guidelines, protocols, WHO rules)
- Negotiations with pharmaceutical companies are necessary
- Each government must have a strong pharmaceutical policy to avoid black market
- Advocacy for social, ethical and structural issues
- Advocate with governments about their responsibilities
- Commitment for debt relief.

What should not be done?

- To develop a parallel system of health care as Church-related organisations
- To work in competition among local NGOs and/or donors
- Allocate funds to one program and neglect the other
- Deliver funds without guidelines to a program
- Integration of both programs at an administrative level
- Do not mix up the two diseases at both donor and operational level
- Deliver drugs and equipment without a program
- To start TB treatment when adequate treatment is not possible (availability of drugs, laboratory facilities, etc.)
- Not filling the gap, but closing it!
- To introduce multidrug antiviral therapy in developing countries, if monitoring and related facilities are not in place

Suggestions and Recommendations in Respect to the MEDICAL SECTOR

Commitment	Knowledge	<ul style="list-style-type: none"> Promote education/awareness raising regarding TB (field) Agencies need to promote and support education and development-oriented TB and HIV prevention <ul style="list-style-type: none"> In this context, poverty eradication, food security, adequate housing and hygiene, economic stability, gender parity and integrated human development must be promoted as solutions to the spread of TB and HIV Advocacy should be an integral part of this effort Guidance of projects by donor organisations to be improved (e.g. answering letters) Donors should exploit potential benefits from synergies (e.g. GLRA TB/leprosy) Training should be based on task analysis Programs active in HIV/AIDS should also be trained on TB, and the other way around
	Resources	<ul style="list-style-type: none"> HIV/AIDS/TB should be a priority for church-related organisations, CI/CIDSE and other donors. Reasons: <ul style="list-style-type: none"> Sufferers (patients and their families) Increasing TB epidemic: risk of it getting out of control Increasing poverty and reversal of the achievements on health and development Church-specific response to root causes International agencies are reminded to increase their efforts in TB control Donor agencies, implementing agencies and communities need to recognise and respond to AIDS/TB as major, inter-related problems Agencies, which wish to support and implement TB treatment must have a commitment which leads to TB cure -- not to incomplete treatment. This implies the following: <ul style="list-style-type: none"> Infrastructure, medications, assurance of quality of care by appropriate training and skills development, provision of technical equipment, and proper follow-up Prevention of incomplete treatment to avoid development of multi-drug resistance Collaboration with other agencies Avoidance of unconnected or overlapping projects Donor commitment should be long-term There must be a long-term commitment to adequate and appropriate care and prevention of TB and HIV/AIDS <ul style="list-style-type: none"> Where feasible, an integrated approach should be seriously considered This approach should be mutually beneficial and not result in reduction of funding Relevant incentives (plus moral support) for partner staff are to be considered
Structures	International	<ul style="list-style-type: none"> NGO efforts have to be concerted with government and among donors (full integration of TB services with health services)
	National	<ul style="list-style-type: none"> Guidance of projects by donor organisations need to be improved (like answering letters)
	Local	<ul style="list-style-type: none"> Support the laboratory facilities, upgrading staff, etc., for TB and HIV control programs

Operations	<ul style="list-style-type: none">• CI/CIDSE endorses, supports and feels obliged to participate in the DOTS strategy where there is a national control policy• H/A programs should be equitably integrated into community health programs (all)• Public health approach should be used for TB as well as for HIV in order to make best use of resources (all)• Goals should be set locally by individual groups regarding the commitment to priority areas and should be shared with the responsible body (all)• Guidance of projects by donor organisations to be improved (like answering letters)• Donors should also consider qualitative assessments in their evaluation, not only focus on quantifiable indicators
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Suggestions and Recommendations in Respect to the SOCIAL SECTOR

Commitment	Knowledge	<ul style="list-style-type: none">• Agencies need to promote and support education and development-oriented TB and HIV prevention<ul style="list-style-type: none">- In this context, poverty eradication, food security, adequate housing and hygiene, economic stability, gender parity and integrated human development must be promoted as solutions to the spread of TB and HIV- Advocacy should be an integral part of this effort
	Resources	<ul style="list-style-type: none">• Donor agencies, implementing agencies and communities need to recognise and respond to AIDS/TB as major, inter-related problems.• Donor commitment should be long-term.
Structures	International National Local	
Operations		<ul style="list-style-type: none">• Community involvement should be an essential condition for effective AIDS/TB control

Suggestions and Recommendations in Respect to ETHICAL ISSUES

Commitment	Knowledge	<ul style="list-style-type: none">• Need to promote deeper reflection on the theological roots of action in response to HIV/TB<ul style="list-style-type: none">- This reflection should involve both church leadership and the membership of local church communities- Efforts should be supported toward interfaith and inter-denominational co-operation and dialogue
	Resources	<ul style="list-style-type: none">• Goals should be set locally by individual groups regarding the commitment to priority areas and should be shared with the responsible body (all)• Forcibly advocate with the ministries of health for sustainable quality TB control and care for people living with HIV through the national programs (field)

Structures	International	<ul style="list-style-type: none"> • Campaign for more equitable policies on health and development • CI/CIDSE lobby for regulating the private sector under government control with major international donors • Advocacy concerning the effects of globalisation and structure adjustment on the health of the poor, particular T/H • Support of the Jubilee 2000 debt relief campaign. • Lobby for debt relief campaign with the local government (all) • NB: Poverty alleviation is not enough for combating T/H! • NB: HIV/AIDS support should not be given at the expense of TB!
	National	
	Local	
Operations		<ul style="list-style-type: none"> • Lobby for debt relief campaign with the local government (all) • Need to promote deeper reflection on the theological roots of action in response to HIV/TB <ul style="list-style-type: none"> - This reflection should involve both church leadership and the membership of local church communities - Efforts should be supported toward interfaith and inter-denominational co-operation and dialogue • Moral support for partner staff to be considered

Suggestions and Recommendations in Respect to the Structures

Commitment	Knowledge	<ul style="list-style-type: none"> • Two representatives – one from a northern country and one from a southern country to present the results of the conference to the Pontifical Council for Health Care and request that it should be distributed to all Bishops' Conferences in the world and also to all Catholic health institutions • Guidance of projects by donor organisations to be improved (like answering letters)
	Resources	<ul style="list-style-type: none"> • More specific commitment to TB/HIV (T/H) through CI/CIDSE • Forcibly advocate with the ministries of health for sustainable quality T/H care through the national programs (field) • Insist on the following as prerequisites for funding to governments (donors): <ul style="list-style-type: none"> - Availability of updated information to all players involved - A portion of this funding should be allocated to NGO level activities • Donor agencies, implementing agencies and communities need to recognise and respond to AIDS/TB as major, inter-related problems

Structures		<ul style="list-style-type: none">• CI/CIDSE should have a working group on TB/ HIV/ AIDS in order to publicise the outcome of the conference. It should be put into the Caritas work plan at the General Assembly• The proposed working group should elaborate a draft policy and an agenda for action.• CI/CIDSE should have a representative at WHO to advocate for health issues and also CI/CIDSE should promote people as applicators in developing countries• Designate an international body to be responsible for the following:<ul style="list-style-type: none">- Select specific areas for priority attention until the year 2000- Follow-up on these priority areas in regard to performance by bi-laterals, multi-laterals and implementing NGO's- Communication between grass roots and international bodies regarding important aspects of implementation and experiences• Reservation: In doing the above we are concerned that a balance of power be maintained which allows partners to fully participate in the process• Adequate solutions need to be based on true partnerships<ul style="list-style-type: none">- Need to commit to community-based rather than "top down" approaches- Co-operation and consultation with national and local government, appropriate agencies (WHO, UNAIDS, IUATLD, etc.)• Donors should exploit potential benefits from synergies (like GLRA TP/leprosy)• More co-ordination between donors to create cross-fertilisation of strengths (lead agency, AFNG as an example); one report for group of donors; exchange of information – travel report
	International	
	National	
	Local	
Operations		<ul style="list-style-type: none">• Document and exchange information, experiences of innovative programs through Web sites, e-mail, booklets, videos, conferences, visits, etc.• Results of innovative programs should be published in scientific journals• Advocacy by the big organisations (especially CI/CIDSE, CAFOD) like debt relief, Jubilee 2000, to repeatedly address responsibility

Elements of an Agenda for Action

- Two representatives -- one from a northern country and one from a southern country should present the results of the conference to the Pontifical Council for Health Care and request that it should be distributed to all Bishops' Conferences in the world and also to all Catholic health institutions
- CI/CIDSE organisations need to designate an international body to be responsible for the follow-up of the conference
- Reservation: In doing the above we are concerned that a balance of power be maintained which allows partners to fully participate in the process
- CI/CIDSE should have a working group on TB/HIV/AIDS in order to publicise the outcome of the conference. It should be put into the Caritas work plan at the General Assembly
- Working Group for both deciders and donors
- The proposed working group should elaborate a draft policy and an agenda for action
- Working group for action plan making and for advocacy
- Select specific areas for priority attention until the year 2000
- Follow-up on these priority areas in regard to performance by bi-laterals, multi-laterals and implementing NGOs
- Workshop to establish co-ordination between deciders and other partners like NGO's and Church's institutions
- CI/CIDSE organisations need to organise training courses of the health workers about these two matters
- CI/CIDSE organisations need to draft a development plan to support basic health problems (lab. drug supplies) or basic health needs
- Improve communication between grass roots and international bodies regarding important aspects of implementation and experiences
- CI/CIDSE should have a representative at WHO to advocate for health issues and also CI/CIDSE should promote people as applicators in developing countries
- CI/CIDSE should campaign for more equitable policies on health and development
- Advocacy concerning the effects of globalisation and structure adjustment on the health of the poor, particular T/H
- Support of the Jubilee 2000 debt relief campaign.

OVERVIEW OVER THE RESULTS OF THE WRITTEN EVALUATIONS OF THE CI/CIDSE CONFERENCE ON TB AND HIV "THE CHALLENGE OF CURE AND CARE"

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The respective questionnaire "Evaluation Sheet" had been handed to each participant. It addressed questions in connection with the overall planning of the conference and its organisation as well as regarding content of presentations and group work. In addition, open questions were asked regarding general strengths and weaknesses, as well as future follow-up of the conference.

Results

Only 34 out of the 90 sheets handed out (37,8%) were returned. Among them there were 11 representatives from developing countries, 9 delegates from CI/CIDSE, AIDS task force or related organisations, one facilitator from one of the International organisations such as WHO, IUALTD, KNCV or GLRA and 3 representatives from the Medical Mission Institute.

Planning of the conference

The majority of respondents felt that their needs were well reflected in the program even though a number of them appeared to have been only roughly informed about aims and contents beforehand and did not make respective suggestions during the planning period for the conference. The tight time schedule was seen as a problem for discussions as well as for informal exchange. Occasionally, the rather technical approach was criticised. While the mixture of presentations and workshop was generally welcomed, there was the request to extend group work rather and shorten time reserved for presentations.

Organisation of the conference

Written information as well as direct support by staff of the MMI was helpful for orientation in Wuerzburg and during the conference. The conference map was appreciated by respondents. Accommodation and transport facilities were adequate, meals were rated acceptable. While the conference venue for the plenary session served its purpose well, the group work suffered where two groups had to share one room. The wide variety of expectations regarding prayer services were met only in part.

Presentations

The majority of respondents rated most presentations overall as good or better in regard to the importance of the topic as well as their content. However, if assessed in detail, a single presentation may have ratings from "poor" to "very good", reflecting again the wide variety of participants with their differing expectations and experiences.

Experiences from community based work were presented to a very limited extent only. Here it was suggested that room should have been given not only to "success" but also to "problems/failures" of this approach.

Discussions and Working groups

The mixture of participants with various background was highly appreciated. Concern, however, was expressed because

people living with HIV were not specifically invited. Also representatives from the government sector with its important role in TB control were missed. It appears that the experience of mutual acceptance and sharing insights between people from developing countries and representatives from donor agencies was a positive one.

Most comments regarding group work were made in the section of the evaluation sheet which contained open questions. Many respondents felt that the aim of the group work was not stated clearly enough in respect to possible future developments based on results. The frame for categorisation of various aspects under three headings, which had been provided as a working guide, did not make things easier and the comparatively little time available has obviously created some undue pressure. Many respondent deplore the lack of a conclusion or a resolution which could be the basis for further action.

Follow-up

Respondents considered the investment into this conference in itself already worthwhile. Others added that an intensive follow-up of the conference would help to even better justify investment of the high expenses involved. Such follow-up should not only refer to the papers/presentations and recommendations formulated by the workgroups which should be made available to all participants but should also further action on transforming results of the group work into activities and even result in formulation of a policy paper.

Suggestions to support such further action on the relevant issues by creating a platform are numerous. Such a platform would possibly have the task to inform about and/or co-ordinate CBO/NGO activities and to advocate/lobby at international level. It may also serve as an advisory body for those to get involved

with projects. Participants suggested to assess achievements after a certain period of time.

Some respondents have emphasised their willingness to follow-up on these issues locally and roughly two third of them have indicated that their technical equipment allows for making use of material provided on a floppy disc. Others would be able to photocopy material for distribution, however, costs for paper needs consideration then.

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CI/CIDSE Conference on Sustainable Health Care, 1995

SUMMARY OF GROUP REFLECTIONS

Fr. Bob Vitillo

Campaign for Human Development, USCC

Analysis of Problems

CHURCH:

- a theology of Church mission has not been adequately articulated and this has a negative impact on the delineation of appropriate goals and objectives and on quality of Church-based health care
- there is a tendency to concentrate on micro-ethical rather than on macro-ethical issues
- a lack of sufficient openness to community participation and to concertation of efforts with government and non-governmental organizations in the same field often leads to an isolated, "paternalistic", "top-down", institutionally-based and financially and socially non-viable approach
- there is inadequate professional training for leaders and workers in church-based health care, especially in the area of professional and financial management
- there is frequent staff turnover among religious; incapacity of some religious congregations to assure continuity in staff expertise

GOVERNMENT:

- there is a lack of stated vision, mission, analysis, goals and objectives and of political will to promote a health strategy which is based on equity and which favors a community-based approach
- inverted funding policies allocate the vast majority of resources to tertiary care which serves the least numbers of people;
- there are pressures from international financial institutions and from other national priorities (e.g., military)
- there is resistance to allowing local communities to determine their own priorities and to assume responsibility for managing health services in their respective

areas - this leads to vertical programs and dependency mentality

- health professionals are poorly prepared, especially in community-based philosophy and techniques
- insufficient financial resources and inappropriate allocation and use of technology cause additional burdens;
- corruption and dishonesty are present;
- there is a lack of commitment to an inter-sectoral and inter-disciplinary approach to health which addresses the non-biological causes of poor health - e.g., injustice, lack of potable water, civil conflict, rural-to-urban flight, lack of employment opportunities, gender inequity, lack of opportunities for education and integrated human development

NON-GOVERNMENTAL ORGANISATIONS:

- staff and volunteers are not sufficiently trained, especially in the area of community-based health care;
- there is a proliferation of NGOs without clear mission, goals and objectives; competition for scarce resources; risk of falling into a dependency mode; corruption among some

NGOs:

- these organizations tend to be self-perpetuating, at times blocked in traditional approaches which are no longer responsive to present needs, especially on the local level;
- these organizations too often are organized and operate with a "top-down" approach; this can cause inefficient use of resources and irrational assignment of staff responsibilities.

LOCAL COMMUNITIES:

- they lack empowering education and preparation to plan and manage community-based health care;
- there are difficulties with conscientizing, changing mentality and engaging local population in this approach;
- poverty hinders access to health care;
- the lack of accessible community-based health care forces people to inappropriately use more sophisticated levels of health services;
- they suffer from a lack of self-confidence and thus do not have a feeling of ownership;
- there is a lack of harmonization between traditional and "scientific" medical approaches;
- they struggle with a series of social problems which lead to poor health conditions, e.g., poor and inadequate housing, poor sanitation, lack of basic education, isolation and discrimination toward certain ethnic groups, problems in communication (health professionals may not be familiar with local languages and culture).

DONOR AGENCIES:

- they often adopt an emotionally-based or partial response to problems without fully consulting and planning together with the affected communities and populations;
- differing political, financial, and ideological policies cause confusion in the field;
- they often follow a bureaucratic, centralized, and overly rigid approach;
- they tend to shift funding policies without prior planning with those receiving funds and without adequate explanation for such decisions;
- they do not always perform critical analysis of the local situation, context, and culture before making decisions about funding;
- they tend to prefer vertical programs because these are easier to monitor but are not always

well adapted and attentive to the local situation.

INTERNATIONAL STRUCTURES - MACRO-ECONOMIC INFLUENCE ON HEALTH CARE:

- Structural Adjustment Programs, imposed as a result of the debt crisis, often dictate a decrease in government health care allotments in the national budget;
- multi-national pharmaceutical industries exploit countries with less financial resources and discourage the use of generic medications;
- countries with greater financial resources make funding decisions on international aid and development based on foreign policy considerations and do not sufficiently support health and social services.

Roles and Responsibilities

CHURCH (with a theological, sociological, and legal character - including all persons (laypersons, religious, clergy) who believe in Jesus, follow his teachings, celebrate his sacraments, and continue his mission of establishing the Reign of God by word and witness - has some characteristics of non-governmental organizations, especially in its human development and health-related services, but also accounts to the higher power of God)

- insure the continuation of Jesus' healing mission through solidarity with all of humanity, but especially with the most disadvantaged;
- promote sustainable health care for all by:
 - * advocating from a value-based perspective with governments and society-at-large,
 - * re-defining and re-orienting its own service institutions,
 - * offering integrated, holistic health-related education and services in partnership with governments and non-governmental organizations with a similar mission,
 - * adequately training staff and volunteers engaged in church-based health care efforts,

- * providing for appropriate and accountable management of its services,
- * encouraging a community-based reflection on micro- and macro-ethical issues,
- *promoting and collaborating with community-based planning and management of health care,
- *assisting the voiceless to express their needs and to be empowered in the active solution of their problems.

GOVERNMENT:

- recognize and respect the basic human right of health care for all;
- design policies and set norms which will guarantee this basic human right;
- mobilize adequate resources and make appropriate allocations to insure community-based health care for all on an equitable basis;
- promote collaboration among various governmental, church-related, and non-governmental organizations involved in health care education and delivery of services and monitor the quality of such services;
- ensure the supply of basic medications, health supplies and equipment, and well-motivated and adequately-paid health care workers at all levels of health service delivery system, but especially at the level of local communities;
- promote dialogue and collaboration with traditional health practitioners and promote better understanding of traditional medicine, especially on the level of local communities;
- collect data related to trends in health;
- provide for international representation and advocacy on behalf of the health and social needs of its citizens.

NON-GOVERNMENTAL ORGANISATIONS:

- advocate, especially in the area of policy development and in the articulation of new models of health care;
- empower and educate local communities to prepare them to assume responsibility for their own health needs and for management of locally-based services;
- sponsor and deliver health-related education and services which are complementary to,

but not duplicative of, similar efforts by the government, non-governmental organizations, and local communities.

DONOR AGENCIES

- to advocate on behalf of partner and member organizations which deliver health-related education and services and on behalf of the communities which they serve;
- make themselves available to humbly and honestly listen to and respond to the needs of local communities;
- participate in the development of community-based health care;
- share resources (financial, technical, and human) with those most in need;
- avoid imposition of ideological or philosophical approaches which do not conform to local needs and realities;
- network with other donor agencies, governments, and institutions in order to avoid duplication or conflict in collaboration with local partners.

LOCAL COMMUNITY:

- study, articulate, and formulate plans based on the needs and preferences of the local population (includes the collection of basic statistics on health and social conditions);
- mobilize local resources and external assistance (when needed and appropriate);
- devise innovative partnerships in order to assure adequate health care for all local citizens;
- respect free choice, culture, capacity and will of local citizens;
- organize and maintain responsibility for locally-based health education and services;
- monitor and evaluate the results of health actions on the local level;
- follow basic planning methodologies:
 - articulation of hopes, dreams and vision as a community.

- identification of needs/problem analysis,
- prioritization of needs,
- identification of solutions,
- planning, implementing, evaluating.

Characteristics of Sustainable Health Care

- basic agreement with traditionally-accepted principles of the 5 "A's"
- other characteristics to which attention should be called:
 - social acceptability (community owned and managed)
 - political stability (rooted in representative community body)
 - economic viability (optimal use of local resources)
 - respect for ecology
 - cultural appropriateness
 - oriented toward liberation rather than dependency
 - based on the principles of interdependency and solidarity
 - equity, empowerment, efficiency, effectiveness

Recommendations for Future Lines of Action

1. The Church leaders need to promote a coordinated approach to health care which includes:
 - improved coordination structures with the capacity to represent the needs of church-based health services, facilitate their mutual collaboration and enable the coordinated procurement of medications, equipment, and supplies;
 - promotion of inter-sectoral collaboration among medical, pastoral, and social development offices, agencies, institutions, and workers;
 - openness to cooperation with government, non-governmental organizations with similar missions and activities;
 - formation of laity, religious, and clergy who are involved in provision of health care and other pastoral and social services;

2. National and international church-related structures need to undertake advocacy efforts to address the root causes of poor health which are found in inadequate social development and to eliminate unjust and inequitable policies which lead to the further impoverishment of those who already the most vulnerable.

3. All those who are involved in providing for health care (governments, international structures, churches, non-governmental organizations, donor agencies, and local communities) need to encourage and facilitate people's participation and involvement in:

- assessment of local health situations
- identification and prioritization of problems
- identification of local resources
- building community-based organizational structures

4. Governments need to launch a process of transformation of health services which is attentive to:

- locally-defined needs and plans
- appropriate technology
- traditional medicine
- cost-effectiveness

5. All those involved in the provision of health care need to plan high quality services which:

- are based on good management principles
- are acceptable to the local populations whom they serve
- are holistic
- employ a friendly and caring approach
- make available essential medications
- offer health care financing options and have affordable user fees
- employ competent and qualified personnel
- utilize referrals to appropriate services which are based on a intra- and inter-sectoral partnerships
- are gender sensitive.

6. Donor organizations need to explore possibilities of providing long-term financial commitments which are open to funding recurrent costs.

7. Those receiving funds need to create an enabling environment for community participation in the identification, implementation, and evaluation of locally-based

community health care and to promote greater coordination and collaboration among the various sponsors of health care on local and national levels.

8. The sponsors and participants in this Workshop need to ensure:

- that a report of the plenary presentations, group reflections, and recommendations be prepared by a small team, published, and disseminated widely;
- that a process of further reflection and sharing of experiences, information and

insights related to sustainability of health care be continued on local, national, regional, and global levels be initiated and implemented.

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FIGURES AND TABLES

Figure 1:

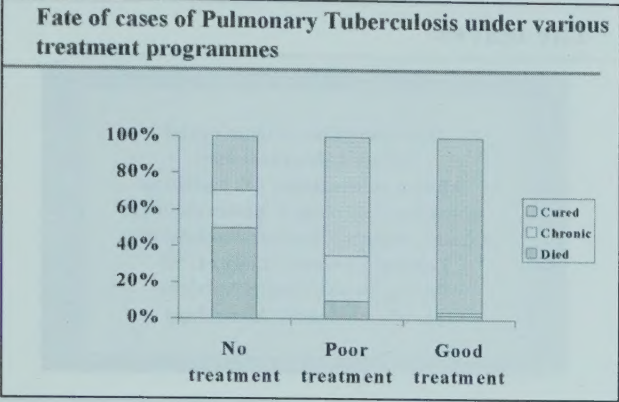


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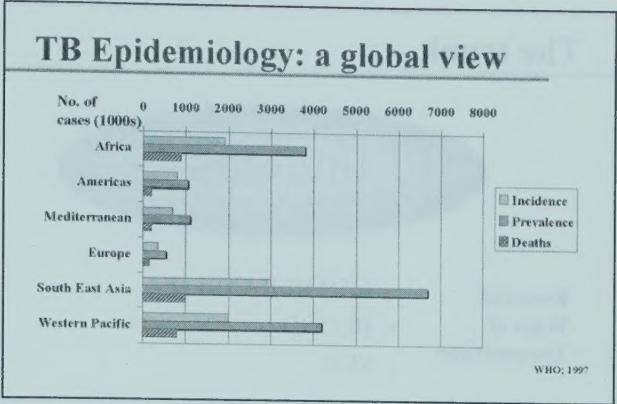


Figure 3:

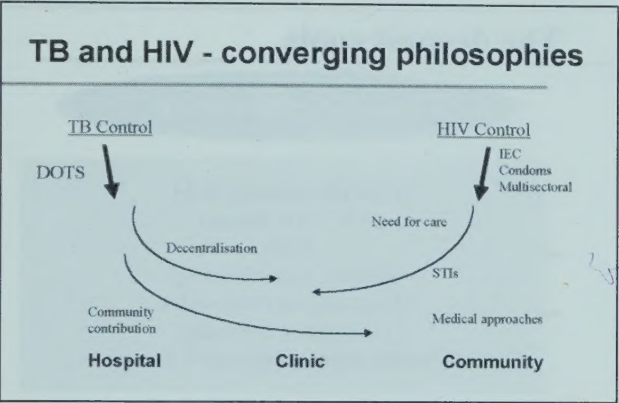


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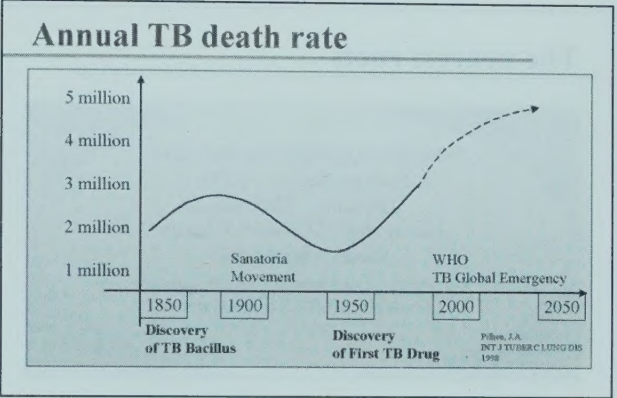


Figure 6:

Tuberculosis - global epidemiology

Region	Incidence rate (.../100.000)	Mortality	Rate of Infection
South-East Asia	247	35%	1,0-2,5%
Africa	293	40%	1,0-2,5%
Latin America	120	20%	0,5-1,5%
Eastern Europe	48	15%	no data.%
Industr.Countries	24	7%	0,01-0,1%

Quelle: Diesfeld, 1996

Figure 7:

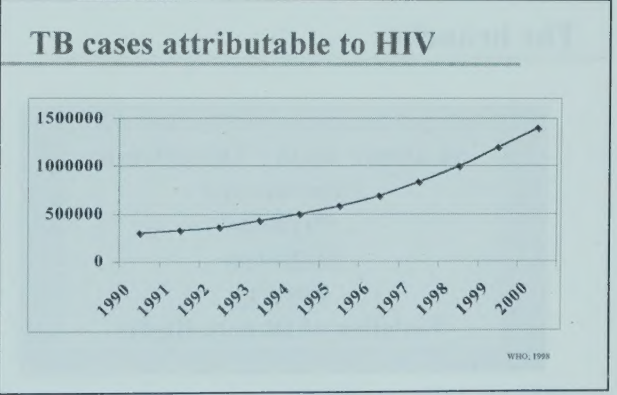
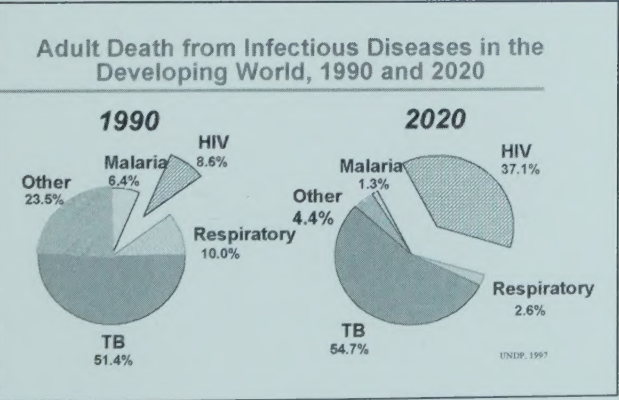


Figure 8:



THE ROOT MODEL

